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# AUTONOMY AND EMPOWERMENT OF HOSPITALIZED OLDER PEOPLE

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Ph.D.

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Autonomy and empowerment of  
hospitalized older people

Dulce dos Santos Gaspar Cabete

A thesis submitted in partial fulfilment  
of the requirements of the University of  
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## **ABSTRACT**

Autonomy and empowerment are core concerns in the field of geriatric care yet difficult to define as they may have different meanings to different people in different contexts. Moreover, discussion has been mostly based on the health professionals' point of view and in the context of long-term care. Hence, the aim of this study was to explore the concept of autonomy and the empowerment process in hospitalized older people encompassing the nurses' and patients' points of view. A qualitative study design was drawn up within a phenomenological approach. Participants were twenty volunteer nurses caring for older inpatients in the context of acute care settings and sixteen hospitalized older patients aged from 67 to 91 years old selected by intentional sample in a general hospital. Data collection was accomplished by conducting a biographic seminar over a semester with nurses and collecting oral narratives, written narratives, nurses' diary notes and unstructured interviews. Data collection with patients was performed through unstructured biographic interviews. Hermeneutic analysis was performed. The main conclusions reveal that these two groups, patients and nurses, have different concepts from each other regarding autonomy and empowerment. Even though the nurses' concept of autonomy encompasses decision-making and self-determination dimensions, it is centred on functional performance and the concept of empowerment is largely unknown. Hospitalized older people have a more comprehensive view of these concepts but feel powerless, voiceless and would like to hold more power regarding the dimensions of care that are currently dependent on nurses' action. In hospital latent autonomy (the existing skills and willingness) is significantly higher than manifest autonomy (that which is accomplished) and nurses play a significant role in the extent of the gap between these two dimensions. Hence, it is fundamental to increase nurses' awareness regarding the need to develop empowering interventions that might transform patients' latent autonomy into one that is vivid and manifest. Further research is needed to expand this differentiation of latent and manifest autonomy, which emerged in this study, either in similar or different contexts of care.



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## **Dedication**

To Rute and Sara,  
for being part of this journey  
and for endless support and love.

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I am overwhelmingly thankful to patients who shared pieces of their lives with a stranger nurse. They opened their hearts, asked questions, shared knowledge and were really active participants in this research. They are the main reason for this research and I hope somehow it may help to enlarge nurses' awareness of how nursing care may contribute to older people's empowerment and to a more friendly hospital environment.

I am also very thankful to my family and friends for their unwavering encouragement, support, love and patience which helped me to go on, even at very difficult moments. I will always be deeply grateful to Rute, who believed in me and whose support, commitment, strength and perseverance were essential to my accomplishing this project.

Finally, I would like to acknowledge the contribution of all older people who passed through my life and stayed forever. They are part of my identity, my beliefs, my personality, my way of being me. They taught me to be as I am, and they gave me the eyes through which I see the world.

## **Author's declaration**

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work.

Dulce dos Santos Gaspar Cabete

Date: \_\_\_\_\_

Signature: \_\_\_\_\_

## FOREWORD

My eyes: just a pair of eyes through which I see the world. Through my unique eyes I see landscapes that maybe others (with other eyes) do not see. Landscapes or flowers... Flowers or roads... Where I see roads, others may see stones... Where I see gates, others may see barriers... With my eyes I see...

*Dulce Cabete*

It is quite usual to start a research report by explicating the motivations and reasons that led the researcher to undertake such work. However, is not so common to start with autobiography, as it might not be so relevant to know who the researcher is. However, each piece of research is unique, as unique as the researcher; and while in quantitative research it may be argued that the researcher's personal history does not significantly influence research results, in qualitative research it is largely accepted that the researcher is part of the research. Namely, in hermeneutic phenomenology, where the attempt is to understand the meaning of life events in a specific context, to try to achieve an insight into certain phenomena, it is vital to make explicit the researcher's knowledge, beliefs and experiences.

As this research arises from life stories of nurses and patients, it seems appropriate to start it by presenting my own beliefs related to my life and background. I am not going to report either biographic descriptive notes or a curriculum: I shall merely highlight some facts, analysing and interpreting their meaning to me, trying to present a portrait of beliefs that have influenced my choice as researcher.

### **My story...**

I was born in 1961 into a traditional Portuguese Protestant middle class family in a Roman Catholic country (Portugal). Since I can remember, to be "Protestant", namely Presbyterian, was a mark, for better and for worse. It was at that time (and

even is now) synonymous with being different, strange, unknown and even weird. As far as I can remember, to be Presbyterian meant to me (as a child) to belong to a community of very nice people, to go to Sunday school, to have lots of friends, to celebrate holidays.

Sunday school was my favourite time: I discussed numerous issues and learned to think critically, to go beyond the obvious and not to judge anyone by his or her age, colour, political ideas, religion or whatever. I learned that no matter how different people may be, they are all entitled to respect and that we must keep an open mind. I learned that we should always try to be better persons and that study is a tool essential to human growth. I learned that, as Christians, we should seek to help others and we should fight against poverty, injustice, discrimination and violence. I learned the meaning of solidarity, not through preaching but through examples. I learned the meaning of generosity by working hard to achieve group goals and by sharing skills. I also learned that “to love each other” is not simply a slogan but a way of life: it is “to know” and “to be” not only in church, but in everyday life. As Martin Luther said, “good actions do not make good Christians, but good Christians will do good actions”. I learned that our actions speak for us.

Today, these are still my deepest beliefs: not to connive at injustice or discrimination but to seek for a better world, here and now. Thus, I did not understand why I was labelled as “the Protestant” with a negative connotation, as “the black sheep” in a white flock. I did not understand why the mothers of other children did not want them to play with me... just because I was “Protestant”. I once heard the schoolteacher saying to a mother... “You should not leave your daughter to play with Dulce!” “But why?” she asked, “she is very cute, isn’t she a good girl?”, “Yes” said the teacher, “she is intelligent and a good student! But you know... she’s Protestant!”

Those words really did hurt me and made me start thinking about differences (Protestant in a Catholic world!). Now I am able to understand that I lived in a

closed society, where democracy was a forbidden word in a dictionary, where to be politically or ideologically different was a risk to life, not only by belonging to a different church but by belonging to an organization that spoke up for human rights, pointed out social injustices and claimed freedom of thought and speech. I remember that some Protestant ministers were arrested and tortured in Portugal in those days just because they preached equal rights, solidarity and freedom. In those days, freedom was just a forbidden word in the dictionary.

Owing to all of the above, I also learnt to value silence. Sometimes, it was important not to talk in school about our family discussions regarding politics or society as it would bring nothing but trouble. I also remember that my father was approached by political police just because he complained about a long 12-hour working journey. When one is alone it is better to keep silent. However, this silence also meant for me that I was able to learn from others: from teachers, from ministers, from colleagues, from people in the street. Silence allows us to observe, to think, to question and I remember, since I was little, that I had loved to watch, to observe and to question why. My sister used to say that at any time I always had an extra question. I discovered the power of silence and the power of words.

Portugal was not a place of freedom: its citizens were supposed to accept that the government was good, that rules were to be obeyed (and never questioned), that colonial war in Africa was fair because it defended our (presumed) interests, that good citizens were Roman Catholic and that the ideal for a woman was to have a “happy family” (whatever that meant) and not a career. All this was the opposite of what I learned in church, where leaders were elected and decisions were discussed and voted on, where there was no such thing as absolute truth, where war was always a nonsense, where rules were to be discussed and not to be obeyed blindly and where men and women had equal rights and “good citizens” were those who loved their neighbour, in spite of their colour and of whatever affiliation.

I was 13 years old when democracy came to Portugal (1974): the teenage time of questioning everything, the time to contest. Simultaneously, in Portugal it was the time of revolution and of major social and political changes. However, the non Roman Catholic population still represented a scant 2% of the population; thus, I continued to feel different. The main difference: I could speak and I could talk about my own beliefs.

My relation to or particular interest in older persons has been present ever since I can remember. When I was born, both of my parents were 42 years old, my brother was 17 and my sister 12. Thus, all of them were “aged” to me when I was a child. I remember one day being in the schoolyard and one of my fellow pupils yelled “Your grandmother is here!” I felt upset, uncomfortable. It made me think about stereotypes because even though my mother was older than the others she was nothing different (I believed). And even if she was different it shouldn’t be pointed out (I believed). I learned the risk of labelling.

I also remember that, from a very young age (from 4 years old), I loved to talk to older persons. I met some intellectual personalities of my country. Two of them were my neighbours and I went very often to their houses, just to talk, to see the books on the shelves, to borrow a few, to ask questions. One of them used to laugh a lot every time I asked “why”. He used to say “You have at least 2 or 3 whys to each answer. It’s good, it’s good...” My mother used to say the same.

“Why are you seated in a wheelchair? Why do you like coffee? Why are you old? Why do you have so many books? Why do you like reading? Why do you always have a blanket on your knees? What does this book say? Why? Why do we have war in Africa? Why are Protestants different? Why?” I certainly learned the



meaning of why. As the music says: “Why have the wings if not to fly? Why have a mind if not to question why?”<sup>1</sup>

My godfather was German Swiss. He was aged 84 when I spent my summer holidays with him and his 86-year old wife. I was 15 and, to me, they were really old. However I could not keep up with him climbing mountains when he decided to walk 3 or 4 hours in the Swiss Alps. I was breathless and he was amused to see that he could walk faster and longer than I could. I learned a great deal, not only about age-related stereotypes of physical strength but also about culture influences on daily life and the complexity of communication. We spoke French (the second language for both of us) but sometimes, even though we used the same words, our worlds behind those words meant different things. I learned the meaning of hermeneutics.

When I was 17 years old, I went to nursing school. Through clinical practice, I started to discover another world, the world of patients and hospitals. I remember a face, a frail body seated in a wooden chair at the end of the ward. Undressed white hair, wrinkles in the face, emptiness in the eyes, sadness in the expression, silence on her lips. No words, though she could speak, no tears in her eyes, though all the physical language expressed psychological pain. What captured my attention? The only clothes she had: a white bed sheet around the thin body, fixed with a large strip of tape over the shoulders. No pyjamas, no underwear, no nothing... just bed linen. Why? “She has no clothes and no family” said the nurses. Where is dignity? Where is nursing care? Who dares to break silence? Who dares to speak for the powerless? Almost thirty years later, the image remains... and the queries too. Who will be able to give a voice to silent people?

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<sup>1</sup> Barbra Streisand’s music “Where is it written” from *Yentl*, 1983

In 25 years as a nurse I have seen old people disregarded, abandoned by society and by family, ignored by health professionals and, somehow, induced to do what nurses considered “the best for them”. Of course, I have also met lots of very happy old people, with family and friends in a good environment. However, even those were often treated paternalistically. I also experienced good nursing care, which evidences that it is possible to have best practice. Thus, I discovered the meaning of powerlessness and the urgent need for empowerment.

Finally, over the past five years, travelling between Portugal and England, I rediscovered the challenges of translation. If in my own language I am not always sure that I really say what I really mean, in a foreign language there are still other barriers to overcome. Hence, all along this journey I have committed myself to the endeavour of translating into words not only my thoughts but the shared experiences of participants in this study who spoke in Portuguese and whose words were translated, proof-read and interpreted. Thus, a double hermeneutic work arose, as any translation is always an interpretation.

# 1. INTRODUCTION

## 1.1. Problem statement and relevance for nursing

It is no longer a novelty to state that individuals and societies are ageing: individuals live longer and, consequently, there are an increasing number of older people, considering absolute figures and the percentage of the whole population. Europe is an ageing continent and Portugal is no exception: according to the Census of 2006 (WHO, 2008a), 22% of Portuguese citizens are over 60 years old, the same as in the UK. As a result, changing patterns of activity arise in society: individuals have different needs and different expectations (Timonen, 2008). However, even though we know and discuss this, often neither individuals nor societies have adjusted to this new reality. It is thus necessary to examine comprehensively the challenges of ageing and to be prepared to act, in order to create a healthy environment for all individuals and health care that is adjusted to those needs.

Ageing brings physical and psychological stress and affects every human being differently; even healthy ageing inevitably carries some physical consequences: although decreasing functional performance through this physical impact only becomes significant over 75 or 80 years of age in a healthy person (Berger and Mailloux-Poirier, 1995, Gallo, *et al.*, 2000, Beers, 2005, Nunes, 2008). Moreover “the ageing process may make people more vulnerable to illness or it may be that living longer allows time for health problems to develop” (Reed, Stanley and Clarke, 2004). Hence, a distinction is made between life expectancy at birth (i.e. the average number of years that a newborn is expected to live if the current mortality rate continues to apply) and healthy life expectancy (i.e. the average number of years that a person can expect to live in “full health” by taking into account years lived in less than full health owing to disease and/or injury) (WHO, 2008). In western European countries, for example, the global life expectancy is

over 80 years of age but the healthy life expectancy is just over 70 years. Using the example of Portugal it may be observed that the overall life expectancy at birth is 79 years but healthy life expectancy is 69 years of age (WHO, 2008).

This means that, at least in the last decade of life people will have to live with disease. Moreover “in the industrialized world, as many as 25% of 65–69 year olds and 50% of 80–84 year olds are affected by two or more chronic health conditions simultaneously” (WHO, 2008b) requiring health care and sometimes hospitalization. However, older adults in hospital have to deal with more than disease. Many face stereotypes of frailty and incapacity and they are often seen as children, who don’t know what the best is for themselves, or like persons without a will (Reich, 1997, Weinman, 1998, Cabete, 2001, Covinsky, *et al.*, 2003, Cabete, 2005a). They have to face nurses’ and doctors’ paternalism and abide by unknown hospital rules (Charles, Gafni and Whelan, 1999, Entwistle and Watt, 2006, Trummer, *et al.*, 2006, Yedidia, 2007).

Furthermore, some studies have shown that at the time of discharge from hospital, older people are less able to function than they were before admission, and that the impact of hospitalization has negative effects on both physical and psychological well-being (Wu, *et al.*, 2000, Beers, 2005). This impact is not related to their disease but to their feeling powerless and being ignored in the decision-making process, which has been related to a reduction in functional abilities and is possibly an indicator of psychological damage (Creditor, 1993, Berger and Mailloux-Poirier, 1995, Creighton, 1995, Shedd, Kobokovich and Slaterry, 1995, Reich, 1997, Gallo *et al.*, 2000, Cabete, 2005b). Yet, maintaining the empowerment of older people decreases dependency on care-giving staff and family members. It also increases the older person’s sense of feeling personally fulfilled, energized, socially meaningful and effective (Meddaugh and Peterson, 1997, Faulkner, 2001a).

Defining empowerment is difficult because it means different things to different people. It is more easily understood by its absence: powerlessness, helplessness, alienation, victimization, subordination, oppression, paternalism, loss of a sense of control, and dependency. Feeling powerless is related to apathy and lack of control over a situation. Moreover, the concept of empowerment remains ambiguous and vague because a critical analysis of its basic premises and underlying meanings and an examination of the concept and practice has been neglected (Davies et al., 2000). Furthermore, existing concept analysis is mainly based on nursing homes, home care or long-term care settings, rather than on acute care. Also, previous studies of hospitalization have relied on professional opinion, neglecting the patients' point of view (Rentsch et al., 2003).

If under the “caring” philosophy of nursing it is assumed that nurses believe that patients have the necessary inner resources to cope with stress and all sorts of life events and see nursing care as a partnership (Collière, 1996, Watson, 1999, Collière, 2001) those in nursing profession should try “to empower older people to make their own choices and set their own agendas” (Reed, Stanley and Clarke, 2004). Thus, nurses play a key-role in the empowerment process, as they spend 24 hours a day with patients and claim to promote patients' autonomy and self-care (Berger and Mailloux-Poirier, 1995, Cabete, 2005b). Nonetheless, it seems that nurses are not sufficiently aware of the concept of empowerment and the implications in geriatric acute care of misusing concepts of dependency and autonomy (Aveyard, 2000, Cabete, 2005b). Hence, an in-depth discussion of patients' and nurses' concepts of empowerment and autonomy is needed and is essential to nursing in the field of acute geriatric care.

## **1.2. Research context**

As the researcher lives and works in Portugal, all the research was conducted there and, although it is not the purpose here to explore cultural differences, some

contextualization is needed; namely general health data and information about nursing education. Portugal is a western European country, having just over 10.5 million inhabitants and a density of 114 inhabitants per square kilometre and registering an annual population growth of 0.5% (WHO, 2008a). The country was founded in 1139, was declared a republic in 1910, and has had a democratic political system since 1974 (Portugal, 2008). Despite recent developments, Portugal registers the lowest Gross National Income Per Capita in Western Europe (21580 US dollars in 2006); however it has an adult literacy rate of 98.3% (2004), with 58% of its whole population living in urban areas (WHO, 2008a).

Regarding health indicators, the country has experienced a significant evolution in the past 30 years embodied in the creation of a national health system “funded by taxation and complemented by public and private insurance schemes and out-of-pocket payments” (WHO, 2008b) in order to answer to the constitutional requirement of a universal right to health care. Now it is possible to show one of the world’s lowest infant mortality rates (3.0 per 1 000 live births in 2006), an achievement acknowledged in the WHO 2008 report as follows:

The system was fully established between 1979 and 1983 and explicitly organized around primary health care principles: a network of health centres staffed by family physicians and nurses progressively covered the entire country. (...) Life expectancy at birth is now 9.2 years more than it was 30 years ago, while the GDP per capita has doubled. Portugal’s performance in reducing mortality in various age groups has been among the world’s most consistently successful over the last 30 years, for example halving infant mortality rates every eight years. (WHO, 2008a)

Despite this evolution, there is still a long way to go regarding nursing care and national health coverage. In fact, general government expenditure on health represents 15.5% of total government expenditure, there are 37 hospital beds per 10,000 inhabitants but there are only 47 nurses per 10,000 inhabitants; a huge shortage if compared to the ratio of 128 in the UK (WHO, 2008a). Regarding hospital care, the country has good coverage for acute care, but numbers of long term or rehabilitation beds are very limited. The national average length of

hospital stay varies between 8.0 days in central and specialized hospitals and 6.5 days in district hospitals, mirroring an acute care focused system and pressure on discharge rates (Portugal, 2006a).

In the context of this research, it is important to bear in mind that more than half of hospital beds are occupied by patients over 65 years old. Therefore, it is expected that health professionals work towards a patient's autonomy, as reduced functional outcomes may compromise home return, with significant impact on health care costs. Therefore, autonomy and empowerment are core issues as they might contribute to improve patient's health outcomes, relevant for both human and economic reasons.

Nursing education in Portugal has changed substantially in the past decades, as it has all over the world. However, the great turning point in Portugal took place in 1974, after the political revolution that completely changed the National Health System, nurses' career and nursing education. From 1974 to 1977, a plan was prepared and a new curriculum for nursing was implemented and since that time there has been only one level of study to become a generalist nurse (Tones, 1998, Nunes, 2003).

Until 1974, different curricula, different levels of education and different academic requirements meant nursing career and practice were a very unequal and inconsistent landscape. In other words, it was possible to find practising nursing care professionals with anything between 6 to 16 years of study, i.e. it was possible to work in nursing care having 4 years in primary school plus 2 years in nursing technical teaching, or having 12 years of basic and secondary studies plus 4 years in nursing school.

From 1977, just one level of nurse education was introduced, in private and in public schools, with a 3-year full time programme to obtain a Nursing Diploma. To be admitted to a Nursing School, an applicant must have acquired at least the 9<sup>th</sup> grade of general studies (high school) and be 18 years of age or over.

However, owing to the small number of vacancies in nursing schools and the large number of candidates, almost all students admitted had the 12<sup>th</sup> grade. Nevertheless, nurses did not acquire an academic degree, as nursing studies were considered a professional, and largely technical, education.

However, in 1989 Nursing Studies were declared superior studies and were integrated into polytechnic institutes, awarding a bachelor's academic degree and maintaining a 3-year curriculum on a full-time basis. To be admitted to Nursing Studies required the 12<sup>th</sup> grade (the same required for admission to university) (Nunes, 2003).

In 1998, another change took place. The structure of the nursing curriculum was changed and the Nursing Superior Diploma was created, based on a 4-year full-time taught programme, resulting in the Degree of Licentiate, in other words an Honour's Degree Diploma (BSc Hons) and the previous curriculum was terminated.

In order to give the nurses having a BSc in Nursing Studies the opportunity to achieve the new academic degree (BSc Hons), a 1-year part-time taught programme designated the "Complementary Year" (Portugal, 1999), was created. Any nurse having a BSc in Nursing Studies could voluntarily apply for this programme. It represents the opportunity to achieve an academic degree, with benefits to one's education and practice, opening the possibility to proceed to Master or PhD studies.

Between 2007 and 2008 all School of Nursing Departments in Portugal adjusted their programme to Bologna requirements, maintaining a four-year, full-time course (UE, 1999, Portugal, 2005).

Thus, in the context of this research we are dealing with graduate nurses having a superior education, including: (1) the development of clinical and critical reasoning, as well as self-assessment skills; (2) the study of ethics and models and theories of nursing. Therefore, it is expected that such nurses are able not only to



understand the concepts of autonomy and empowerment but also to provide excellent care.

### **1.3. Aim and research question**

Through my professional experience over twenty five years (as a care provider, as a head nurse and as a nursing teacher) the issue of autonomy of older people was often brought into discussion and reflection, raising many questions and concerns. On the one hand, in clinical language the expression “to promote one’s autonomy” is continuously heard and written about but, on the other hand nurses’ most common attitude seems to be to ignoring older people’s wishes. And even if in an individual’s care plan it is often written that the patient must assume control over her or his health situation, that patient is often ignored in the decision-making process. Nonetheless, it seems that patients do not always want to make decisions. Sometimes it looks as if they just want to be cared for. Hence many queries crossed my mind over and over: what do nurses really think about empowerment? How do nurses experience patients’ empowerment in everyday life? How do nurses experience older people’s autonomy through nursing care? How often do nurses really listen to older people? How do older people experience hospitalisation vis-à-vis their willingness to be autonomous? How do older people feel regarding empowerment in hospital? Do older patients want to be empowered or is this a theoretical assumption?

Thus, I consider that it is necessary to clarify the concepts of autonomy and empowerment in the context of acute care for older people, giving voice to nurses and to patients by listening to their experiences. Hence, the aim of this study is *to explore the concept of autonomy and the empowerment process in hospitalized older people* in order to answer the question: *How do nurses and older people experience autonomy and the empowerment process in hospital?*

In this way, the study seeks:

- To explore nurses' and older people's concepts of the autonomy and empowerment of hospitalized older people;
- To identify the role of nurses in the impact of hospitalization on older people;
- To explore ways to improve autonomy and empowerment of hospitalized older people, through nursing care.

#### **1.4. Thesis overview**

To develop understanding of the research question "*How do nurses and older people experience autonomy and the empowerment process in hospital?*" a literature review will be presented encompassing a conceptual exploration of autonomy, empowerment and decision-making as well as an examination of the challenges of hospitalization to older people.

Methodological issues and researcher's options will be explored, including research design, data collection process, participant recruitment, ethical implications and resources used. A phenomenological approach was chosen because the aim of this study is to understand (and not to measure) lived experience and its meaning in a situational context (Todres and Wheeler, 2001, Streubert and Carpenter, 2002). An exploratory and analytic study design was used, the focus of this research being a contemporary phenomenon in a real-life context. A method of data collection, biographic narrative work, completed with older patients and nurses, was underpinned by the work of Josso and Dominicé and the researcher's previous experience (Josso, 1991, Dominicé, *et al.*, 1998, Josso, 1999, 2002, Cabete, 2005a, Josso, 2006).

Since the mid-1960s, biographic narratives have been used in research emerging in anthropology and sociology and have spread more recently into health sciences; namely, in nursing research (Josso, 2002). Life histories or narrative inquiry are

methods that gather, analyse and interpret the stories people tell about their lives, seeking to uncover the subjective experience of individuals and the way they understand it (Marshall, 1999). Thus, biographic narrative was considered an adequate tool in the landscape of hermeneutic phenomenology.

In the Findings Chapter, data will be presented, analyzed and interpreted through hermeneutic reflexivity because this is a grounded, reflexive and humanized way to provide insight into existential experience (Gadamer, 1979, Heidegger, 1984, Ricoeur, 1990, Gadamer, 1994, Ricoeur, 2000, Todres and Wheeler, 2001).

In the chapter that follows the main findings will be discussed as a framework for older people's empowerment in hospital, integrating nurses' and patients' points of view. The implications of the study to health care providers will be outlined, as well as recommendations for future studies, and research limitations will also be discussed. The thesis concludes with a critical analysis of aims accomplishment.

## **1.5. Definition of terms**

Within this study, the following terms have been identified and operationally defined:

**Empowerment**: process of recognising and enhancing people's abilities to meet their own needs, solve their own problems and mobilise the necessary resources in order to feel in control of their own lives (Gibson, 1991, Faulkner, 2001a). It is not only the passive receiving of a gift, but an active movement involving both sides: those who have to give it and those who receive and use it.

**Autonomy**: the freedom to decide one's own project in life and the necessary skills in order to accomplish it. It is not the ability to do but the ability to decide what to do. It depends on the opportunities and the freedom to make choices, with the purpose of achieving self-determination encompassing three levels of concepts: autonomy as free action, as effective deliberation, and as consistency

i.e. focusing on the coherence of all decisions and actions reflecting past, present and future goals (Jecker, 1993).

**Older people:** individuals (male or female) aged 65 years or over. In this research, to identify quotations from participant older patients, namely in Findings and Discussion chapters, the capital letter P is used, inside round brackets (P), followed by the number given to each participant.

**Hospitalization:** for the purpose of this study, hospitalization is considered to be admission in a hospital involving a stay of more than 24 hours. It is not specified in terms of motive, type of procedure(s) or hospital classification.

**Nurses:** any individual (male or female) registered with his/her national board that has completed the necessary education i.e. is legally entitled to practice nursing care, either generalist or specialist. In this research, to identify quotations from participant nurses, namely in Findings and Discussion chapters, the capital letter N is used, inside round brackets (N), followed by the number given to each participant.

**Biographic work:** all work performed with participants, based on the use of lived events with educational or research purposes; may be either using individuals' full life history or just fragments of it, either being centred on a specific topic or not, or even being self-directed or guided by the researcher. It includes analysis and interpretation besides the production of narrative material.

**Life histories:** Simultaneously a research and an educational tool, life histories is a methodology that arises from the belief that each individual's story has a meaning bigger than the story in itself. In this research it is used in a broad sense. The work of life histories may be defined as the movement through which an individual transforms lived events into experience.

**Narrative or Story:** excerpt of description of lived experience; may be the narrative of one event or a full life narrative from a single individual.

**OR**: Oral recital produced by participant nurses; a spontaneous narrative of lived events audio recorded by each participant.

**WR**: Written recital; a more organised recital produced by participant nurses.

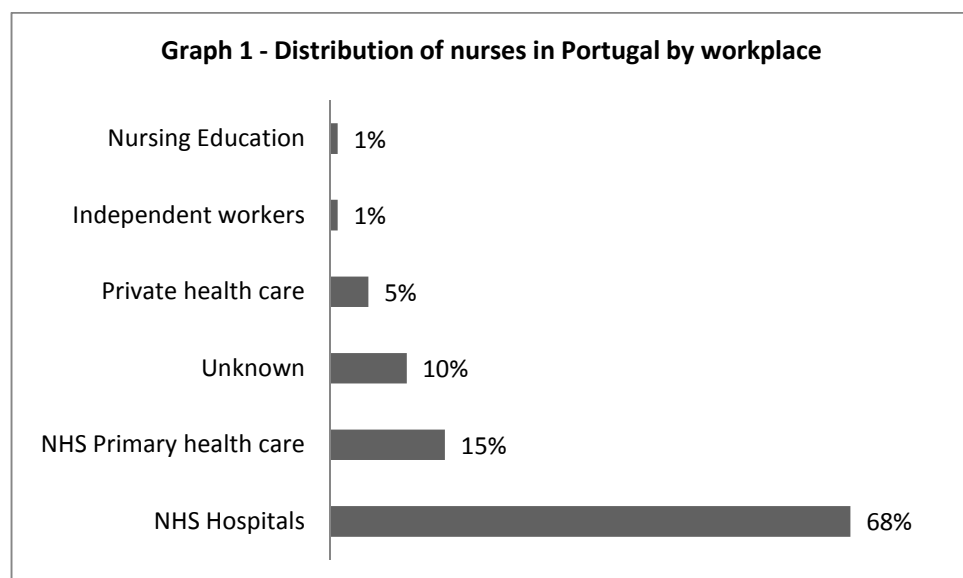
**DN**: Diary notes produced by nurses alongside the biographic work.

**IV**: Interviews' verbatim.

## 2. BIBLIOGRAPHIC OVERVIEW

In an ageing society, a vast range of challenges may capture nurses' attention: biological or psychological aspects of ageing, demographic impact on societies, as well as health care concerns. Nevertheless, the immediate impact on nurses of a demographically older society can be observed in the health care system as older people constituting a substantial proportion of nurses' work in various settings. Moreover, this impact becomes even more significant in hospitals (the working place of a significant number of nurses), where people over 65 years old represent an increasing percentage of clients (Silva, 2006, Nunes, 2008, Timonen, 2008).

According to the Ministry of Health, in Portugal more than half of NHS hospital clients' are older people (Portugal, 2006a). According to the Portuguese Council of Nurses (OE, 2007), 68% of nurses declared that they work in an NHS hospital, as shown in Graph 1 (the true percentage of nurses in hospitals will be higher as hospitals are a significant part of the private health care system and 10% of nurses do not keep updated records).



Thus, understanding older people's needs in hospital settings is a core concern in nursing care. It is also necessary to discuss what nurses have in mind when they care for older people, and there is not an easy answer, as often the nursing care that philosopher nurses write about is rarely achieved in practice. However, in spite of this difficulty it is relevant to search for meaning, working on nurses' conceptual background.

Regarding the aim of care or its underlying philosophy, it may be affirmed that for the modern nursing the debate started with Florence Nightingale, whose work is still used, translated, and discussed (Nightingale, 1969). However, a more structured discussion came with Virginia Henderson in 1968 in answer to a request from the International Council of Nurses (Henderson, 1978, 2007). Henderson defined the aim of nursing care (regardless of context, care provider or client background) as follows:

Nursing is primarily helping people (sick or well) in the performance of those activities contributing to health, or its recovery (or to a peaceful death), that they would perform unaided if they had the necessary strength, will, or knowledge. It is likewise the unique contribution of nursing to help people to be independent of such assistance as soon as possible... The nurse is temporarily the consciousness of the unconscious, the love of life of the suicidal, the leg of the amputee, the eyes of the newly blind, a means of locomotion for the newborn, knowledge and confidence for the young mother, a voice for those too weak to speak, and so on. (Henderson, 1978)

To be “a voice for those too weak to speak” or “to help people to be independent” may be considered as pointers towards empowerment, even if this term was not in use at that time. Moreover, if nursing action is directed to patients' independence it must consider their strength, will and knowledge; conditions underlying empowerment.

Nursing concepts and theories have changed considerably in the past four decades from the categorization paradigm (where nursing care is structured by basic human needs, or activities of daily living) towards the more open view of the transformation paradigm (where nursing care is unique and complex in a never-ending interaction between nurses, patients and a multifaceted and changing

world) (K  rouac, *et al.*, 1994). The more recent theoretical frameworks such as Watson's caring philosophy of nursing, emerged in the transformation paradigm describing nursing care as a subjective interaction (simultaneously an art and a science) where nurses help others to accomplish their life projects (Watson, 1999, Hesbeen, 2004, Honor  , 2004). Here again, nurses are called upon to act towards individuals' self-determination, freedom of choice and control over their lives and unique projects (K  rouac *et al.*, 1994), considering that each person has the inner resources to accomplish this (Watson, 1999). Once more, empowerment encompasses the right to make decisions and to have autonomy. Arguably, empowerment is a core issue in nursing care, in the uniqueness of each person and the complexity of each context.

Given the above, it is necessary to develop the background of this study not only around the concept of empowerment but also the concepts of autonomy and decision-making and their implications for hospitalized older people.

## **2.1. Empowerment**

The concept of empowerment needs to be explored in particular contexts, in different moments and circumstances, having gender, cultural, social, economic and political influences, as an interactive movement that plays a significant role in people's and communities development and well-being (Katz, 1983, Aoki, 2002, Bergland and Narum, 2007, Dube, 2007, Jewell, 2007, Adubra, 2008).

Empowerment is a popular term in contemporary society and a concept present not only in health care but also across many social disciplines. It may be considered a dynamic and transactional concept, involving individuals and their environment, with emphasis on individual self-assertion, domination and control (Browne, 1995, Aoki, 2002, Shearer and Reed, 2004).

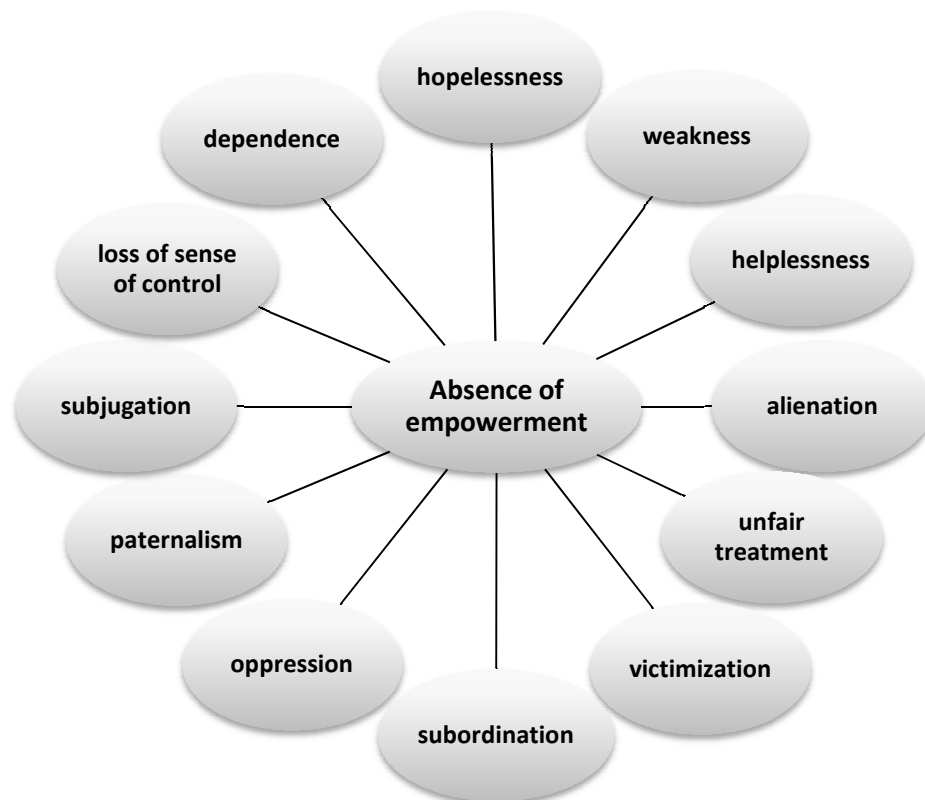
Empowerment... means the process by which individuals, families, groups and communities increase their personal, interpersonal, socio-economic, and political



strength and influence in order to improve their well-being. (...) Empowerment is not granted from an external source but emerges from within as persons and communities acknowledge and appreciate their gifts and their responsibility. (Dube, 2007, citing Giblin, 1996)

Thus, not only is empowerment influenced by environmental factors but through it, it is also possible to shape the environment (Bergland and Narum, 2007). Empowerment is either a process, an intervention or a skill (Browne, 1995, Faulkner, 2001a, Mapanga and Mapanga, 2004), but the concept requires in-depth exploration and reflection on practice (Browne, 1995, Shearer and Reed, 2004).

**Figure 1 - Expressions of lack of empowerment**



Defining empowerment is difficult not only because it means different things to different people but also because it is more easily understood by its absence (Faulkner, 2001a): hopelessness, alienation, unfair treatment, victimization,

subordination, oppression, paternalism, loss of a sense of control, and dependency are some of the terms used to define it. In Figure 1, some expressions found in literature are presented which mirror a lack of empowerment.

Experiencing powerlessness can be related to apathy and depression, to expressions of a lack of control over a situation, to non-participation in care, to indecisiveness and to passivity, which may also be experienced by families and caregivers (Meddaugh and Peterson, 1997). Without empowerment, older people can be influenced, coerced, manipulated, their consent may be violated and autonomy ignored (Faulkner, 2001a).

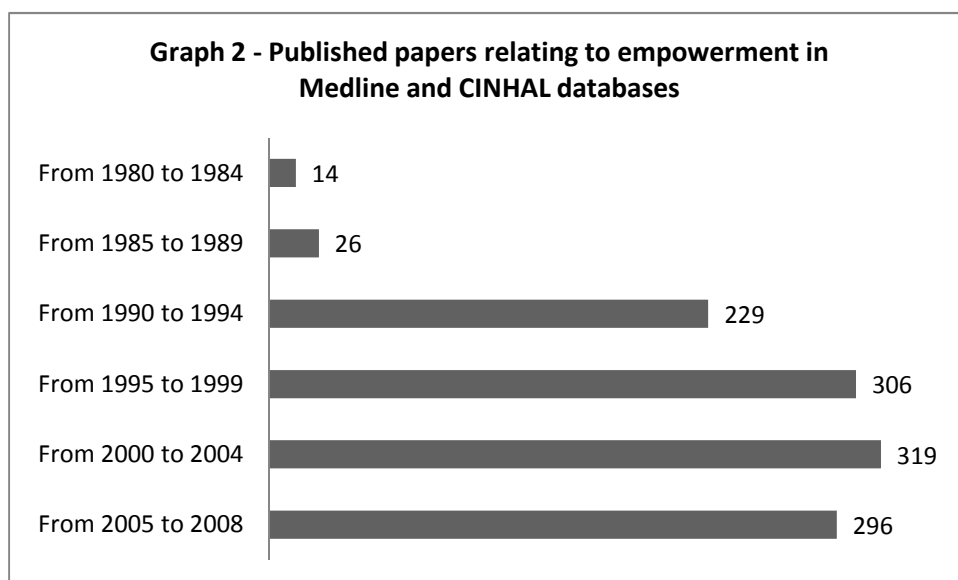
Before trying to define empowerment, it is important to underline that the same word may have different semantics according to the users and to the context of its use. Moreover, defining the meaning of a word is in itself an effort of interpretation (Ricoeur, 2000). Hence, in this study it may be important to consider both the current language meaning and the expanded theoretical meaning. Yet it may be asked if it is appropriate to discuss current language semantics in a scientific paper. Nonetheless, it may be countered that if we are going to explore autonomy and empowerment with patients we must be aware of the everyday use of these words. Even nurses (as ordinary citizens) often use a word with its commonsense meaning, rather than its full theoretical significance. Thus, current language meaning should be considered as a starting point to move on to further and deeper interpretations.

The current meaning of the word empowerment is to give (someone) the power or authority (to do something), and can be considered synonymous with “enable” or “entitle”. Furthermore, “to enable” means the action “to make (someone) able (to do something)” and “to entitle” is “to give (someone) the right (to do something)” (Procter, 1981, p. 360, p. 366, Shearer and Reed, 2004, Wehmeier, 2005). We may consider that, in the current language, the meaning of the word empowerment is not just a status, but an action: to give someone more control

over their own life or the situation they are in (Shearer and Reed, 2004, Wehmeier, 2005).

Thus, empowerment is to give, not to have. It is a movement enacted by someone who possesses the power, and is going to deliver it in order to realise the right of someone else. This would mean that in a one-to-one relationship the “empowerer” must relinquish some power, and this may not be well understood or even comfortable.

In literature, although empowerment is a very popular term it is also a very recent concept as it first appeared in the 1950s, gaining relevance through the two subsequent decades, namely, related to human rights, women’s emancipation movements, and other social challenges (Shearer and Reed, 2004). The concept arose in the 1980s in psychology and mental health fields but only through the 1990s did it start to appear consistently in health literature. This may be confirmed by searching the most relevant databases regarding health and nursing issues.



Using EBSCOhost search engine, a search was performed in the following databases: CINAHL with full text, AMED - The Allied and Complementary Medicine Database and Medline. The only search term used was “empowerment” indexed to the field “article title”. Without using any limits to search results, 1190 articles were retrieved<sup>2</sup>, the first paper dated 1980. Grouping the results by five-year periods it is possible to see the evolution of the number of publications and as shown in Graph 2, only in the 1990’s did the term empowerment appear to be used on a more regular basis.

Looking to the first five years of publications in more detail it is possible to see that none of them is related either to nursing care or to older people. The first article published in the health literature using the term empowerment addresses foster parents’ issues (Jacobs, 1980). The remaining publications address the general concept of social empowerment (Kieffer, 1983, Savo, 1983, Simmons and Parsons, 1983a, Hurty, 1984), community empowerment (Biegel, 1983, Fawcett, *et al.*, 1983, Katz, 1983), management or professional empowerment (ANA, 1982, Brown and Kanter, 1982) or mental health (McGuire, 1983). Only one article addressed age-related empowerment regarding adolescents (Simmons and Parsons, 1983b).

In a broader exploration, NORA<sup>3</sup> was used perform a Boolean search in CINAHL with full text, Medline, Proquest Nursing Journals and Science Direct databases. Using the keyword ‘empowerment’ in the fields ‘title’ OR ‘subject’ 7372 articles were retrieved. Subsequently, the results were refined combining the keywords ‘empowerment’ AND “older people” OR ‘aged patient’. Only 198 articles were found (2.7%), mirroring the scant attention given to the geriatric population. At a

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<sup>2</sup> The search in databases was performed in January 2009.

<sup>3</sup> Northumbria Resources search engine

closer look, it is possible to see that, from 1990 up to 1994, (when the concept began to appear in literature) only 7 registers met these criteria but of these just 4 really focused on empowerment: one related to home care, one regarding nursing homes and only two associated to hospital environment.

The first study, from Brown and Furstenberg (1992), was conducted in USA, in home care, with patients, their families and their home health teams. The conclusions point out that a successful recovery and rehabilitation of the older patient' following a hip fracture

'is contingent upon restoring the patients' perception of control over their recovery. Empowerment is achieved both through the *content* of interventions, and through the *process* by which health professionals work with patients and their families'.

The second publication (1994), is a observational study in two Swedish nursing homes concluded that in spite of 'tender, loving care, strong cohesion and affection between patients and personnel were typical of the observations, yet patients complained of imprisonment, powerlessness and hopelessness'. It also states that empowerment measures must take place at 'organizational, interactional and personal levels'.

The two papers relating to hospitalized patients are both Canadian studies (McWilliam, *et al.*, 1994, Staples, *et al.*, 1994). All these authors state that restrictions to decision-making possibilities, paternalism of professionals and biomedical orientation lead to anger and reduced autonomy. The researchers conclude that 'empowerment strategies must encompass a patient-centered approach, which includes an understanding of the patient's mindset, goals, aspirations, and sense of purpose within a larger life context'(McWilliam *et al.*, 1994). Thus, the discussion around empowerment in care of older people contexts has just begun and needs further exploration, particularly in hospital settings.

Moving through literature review, it may be stated that empowerment encompasses different dimensions, including "those directed to individuals,

among individuals and to the community/society” (Jewell, 2007). Regarding the power of individual people, “empowerment means the restoration of a sense of their own value and strength and their own capacity to handle life’s problems” (Bush & Folger, 1994, cited in Jewell, 2007). In a social and political context, empowerment is viewed as:

a social action process that promotes participation of people, organizations and communities in gaining control over their lives in their community and larger society... not characterised as achieving power to dominate others, but rather power to act with others to effect change (Wallerstein and Bernstein, 1988).

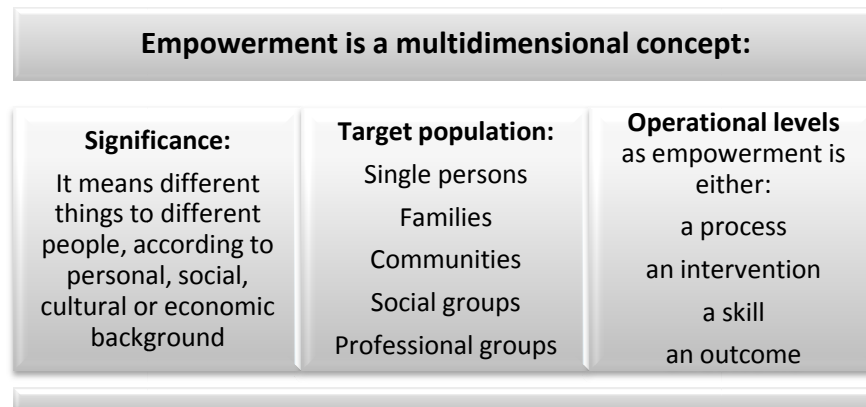
And this process is possible through “recognizing and valuing diversity by genuinely giving people the influence in decisions affecting their future” (Perrons and Skyers, 2003) and a condition to find solutions that reflect the real population’s needs. Nevertheless, according to these same authors, empowerment is largely discursive and difficult to achieve; firstly, because it is difficult to integrate into practice and risks being uneven and, secondly, because it must occur at the level where decisions take place:

Community empowerment implies that people will have the necessary information, as well as power and influence to exercise some control over the future (...)having the freedom to make mistakes (...) as local governments have done for years and have left the community to suffer the consequences (Perrons and Skyers, 2003).

Thus, as summarized in Figure 2, it is possible to say that empowerment is a multidimensional concept in different ways: regarding its significance (because the meaning is contextualized and depends on an individual’s attributes, background and environment), because it has different dynamics and implications according to the target population (single individuals or specific groups) and because it may be described in different operational categories (as a process, an intervention, a skill or an outcome).

Hence, it may be analysed at different levels: individual, organizational, social, cultural and political (Brandon, 2005); however, given the aim of this study, the focus here will be at the individual level.

Figure 2 – Dimensions of the concept of empowerment



Tones (1998) argues that empowerment is a complex concept involving four interacting factors of an individual: environment, competence, perceptions of control and the emotions accompanying these perceptions. According to Buffum (2004), “empowerment improves individuals’ initiative to take actions for their health with confidence, hope and a feeling of self-worth”.

Empowerment is also viewed as a collective right and a duty of participation in decision-making in a community with democratic values, and it has been recognized that it promotes independence and dignity.

Even in health literature, empowerment is often just related to a social activism vis-à-vis community groups in order to overcome some disadvantages (poverty, discrimination, lack of access to education). With unquestionable advantages to health promotion and social development, empowerment is a positive movement to achieve better life conditions and promote social integration. Some examples of this may be given: In the North American context, Kapp (1989) describes empowerment as a movement to encourage some activism among the “capable elders” regarding their own rights and interests, aiming to develop older people’s capacity to speak for themselves; Messias et al (2005) found in their research with

women living in a state of economic poverty (receiving federal help from the USA government and self-reporting low income) that both at the individual and at the community level, well-being was enhanced through social participation; Jewell (2007), in a qualitative study, evidenced that working with Health Brigades (in Nicaragua) influenced the sense of empowerment of women.

Also, in the professional field, empowerment leads to better job satisfaction, better performance and better health. Since 1982 the American Nurses' Association has claimed that nurses' empowerment is fundamental to enable nurses to provide full and adequate nursing care (ANA, 1982). In a Swedish study involving a total of 2011 registered and assistant nurses, using measuring scales of psychological empowerment at the workplace, general mental health, burnout, and sick leave, it was demonstrated that empowerment explained 2–18% of the variation among the nurses with regard to the three types of ill health measures, concluding that “greater psychological empowerment at work corresponds generally to less ill health. Psychological empowerment at work may be one of the many possible factors that provide protection against ill health” (Hochwälder and Brucefors, 2005). Moreover, in a Finnish study involving 137 cancer nurses, it was demonstrated that being adequately heard regarding the changes in the workplace and working with co-workers in a group were related to stronger empowerment and to better working outcomes (Suominen and Rankinen, 2006).

Empowerment is also an issue of interest in the field of consumers' rights; namely, in health service contexts. Sabin, O'Brien, and Daniels (2001) refer to the activism of American health consumers where more emphasis is being given to clients' satisfaction and to rights which are more easily assessed. According to these authors, “although ‘empowerment’ is a less precise concept than ‘rights’ or ‘satisfaction’, it is especially important to consumers, because it connotes (...) a capacity to influence one's destiny” (Sabin, O'Brien and Daniels, 2001). In this context, empowerment means a whole community committed to achieving goals, all parts included: managers, practitioners, providers and community agencies. At



this point, developing a sense of community is one of the most significant aims either in health education issues or broader social participation (Valadez, 2003, Mapanga and Mapanga, 2004, Messias, De Jong and McLoughlin, 2005, Jewell, 2007, Adubra, 2008, Braunack-Mayer and Louise, 2008, Hughey, *et al.*, 2008, Walsh and O'Shea, 2008).

However at this level, we are discussing management where consumers' committees are part of the decision-making process. This means that a group of "healthy" people meet to have a round table discussion of hospital issues, in which each and every participant has an equal seat and (possibly or hopefully) an equal voice and equal power. Nonetheless, the organization of care for older people is largely influenced by economic and political trends, where public versus private sector interests define the intervention lines that might either increase or diminish a patient's power. Scourfield (2007) states that mergers and acquisitions in older people's residential homes in the UK private sector may lead to a reduced consumer voice and less participation in the decision-making process, as residential care rules are dictated by market forces.

This could lead to an interesting discussion, but this is not the core issue of this research, whose interest is to explore the (em)power(ment) of hospitalized older patients "in order to create a knowledge base for practice in a way that challenges professional hegemony and empowers old people" (Reed, Weiner and Cook, 2004).

Despite being a very important issue, social activism as a group action is not often a possibility in a health care delivery system, where patients just have themselves or their families to claim for voice. Hospitalized and sick older adults become vulnerable and powerless with deleterious and critical effects on health and even physical conditions. Alone in a hospital bed, an aged patient does not have a "support team" to claim for her or his rights, if nurses are not able to recognise this need. Moreover, empowering practice is far from being prevalent among "the

21<sup>st</sup>-century nurses of authoritarian and paternalistic approaches” even if it is a “desired goal in nursing” (Shearer and Reed, 2004). Thus, it is important to go through health literature and look for the existing semantics of patient empowerment.

In the health literature, as stated in the introduction, empowerment is described as a social process of recognising and enhancing people’s abilities to meet their own needs, solve their own problems and mobilise the necessary resources in order to feel in control of their own lives (Gibson, 1991, Faulkner, 2001a). Moreover, Bergland (2007) emphasizes the intentionality of the process: it is not only to receive a gift passively, but is an active movement involving both sides: those who have it to give and those who receive and use it. Nevertheless, in the health care context, the focus has been reduced to informed consent for medical procedures or to legal devices “such as the living will and the durable power of attorney, on a prospective basis to effectuate informed consent later in life” (Kapp, 1989).

The concept of empowerment is based on two principles:

- **Knowledge:** without knowing the personal rights, the reasonable alternatives, the outlines of facts and events and the possible risks, decision-making does not make sense;
- **Voluntary acceptance:** it is impossible, or unreasonable, to force someone to make decisions.

Kapp (1989) argues that a significant number of adults would not accept voluntarily to assume all power of decision in significant matters, particularly “life-and-death” ones. Using the expression **forced empowerment**, leads to questioning whether we should not, indeed, recognize the right to depend on others. However, the author states that the “capable elderly” have a duty to assume the responsibility for decision-making processes in health matters

“otherwise they will unnecessarily consume increasingly scarce resources” (Kapp, 1989).

The opposite of forced empowerment is the concept of **forgoing empowerment**, meaning that “capable older persons” may give up the responsibility for decision-making: “choosing dependence on others rather than independence would be a respectable alternative” and also a right (Kapp, 1989). Using the example of financial affairs, the author claims that few of us would question the individual’s right to choose an attorney to manage them, and once he is in a fiduciary relationship with his clients he is ethically and legally obliged to act in his client’s best interests. In the health field, this obligation should be considered in the same way.

However, we must not confuse forgoing empowerment with abdication because we must be sure that patients are perfectly aware about all the implications of this renunciation. It is not to assume passively the “I don’t care” attitude from patients, reinforced by paternalistic medical attitudes. Forgoing empowerment means “I know what I am doing and I trust in you to act in my best interests”. In any case, the issue is having control over one’s life and a clear perception of this control.

Perceived personal control is a construct developed in health psychology encompassing cognitive, decisional and behavioural dimensions, with an important and demonstrated role in physical and mental health and coping with a health condition (Shiloh, *et al.*, 1997, Ayme, Kole and Groft, 2008, McAllister, *et al.*, 2008, Skuladottir and Halldorsdottir, 2008) and it is described as “the belief that one has at one’s disposal a response that can influence the aversiveness of an event” (Thompson, 1981 cited in Shiloh *et al.*, 1997). Nevertheless, despite being an important subject, perceived personal control is not the only dimension of empowerment: the need for having hope for the future and being able to participate in decision-making are also significant (McAllister *et al.*, 2008).

The perception of control in older people has also been related to well-being and improvements in health and health perception by many authors. In a previous study, Shiu (2001) interviewed 18 residents in a nursing home in Hong Kong, finding that they identified the physical environment as promoting privacy and mobility and the approach of the nursing care personnel as promoting of independence, security and self-respect, with a sense of being a family.

One of the main findings of Shiu's study (2001) was the link between participants' perceptions of control and their well-being. They recognised that environment facilitates their autonomy in daily living activities and staff attitudes helped them to be assertive and to make decisions. In the same way, a patient empowering education, focused on knowledge development, supported by a shared decision-making and a real partnership between patients and health professionals, significantly enhances patient compliance to treatment in chronic disease with evident benefits to quality of life (Nielsen, *et al.*, 2008, Rimmer and Rowland, 2008, Zoffmann, Harder and Kirkevold, 2008).

Maintaining the empowerment of older people will decrease dependency on care giving staff and family members and increase among older people the sense of feeling personally fulfilled, energized, socially meaningful and effective (Meddaugh and Peterson, 1997, Faulkner, 2001a, Rimmer and Rowland, 2008). Moreover, empowerment is perceived as a core dimension of quality of life for older people as they "desire to maintain and have control of reciprocal social and community ties" (Bergland and Narum, 2007).

The converse is also true: disempowerment leads to helplessness, dependency and hopelessness. To feel powerless and to be ignored in the decision-making process has been related to a reduction of functional abilities and is possibly an indicator of psychological damage (Creditor, 1993, Berger and Mailloux-Poirier, 1995, Reich, 1997, Faulkner, 2001a, Covinsky *et al.*, 2003, Cabete, 2005b, Rimmer and Rowland, 2008).

According to Meddaugh and Peterson (1997), for empowerment to occur, four essential conditions are needed: autonomy, knowledge, positive self-concept and independence. However, once power is accepted as a transactional concept, there are also prerequisites to this process (Hocks 1991 referred to by Aoki, 2002):

- A situation with more than one person;
- An orientation of power as good;
- Power skills (such as trust, communication skills, knowledge, concern, caring, respect and courtesy);
- Possession of at least one of four power sources: informational, referent, expert or legitimate;

Jewell (2007) adds that self-awareness and self-efficacy are conditions to achieve empowerment. To empower, however, is not a simple process and does not entail happiness for everyone (Aoki, 2002). Moreover, as with any other nursing intervention, it needs to be carefully planned and evaluated and is unique each time it happens.

In hospital settings, staff practices are continuously disempowering patients. The rules, the biomedical culture, the frailty of the patient's condition, the expected "sick role", everything seems to contribute to reducing the patient's power and to increasing the professionals' power to control the situation (Sakalys, 2000, Faulkner, 2001b, 2001a, Leino-Kilpi, *et al.*, 2003, Prilleltensky and Prilleltensky, 2003).

The purpose is not to transfer all the power to patients: the question is finding the necessary balance between professionals' and patients' power. Although the importance of patients' empowerment has been widely highlighted, it seems that, in some particular situations, it is hard to achieve, or even to consider.

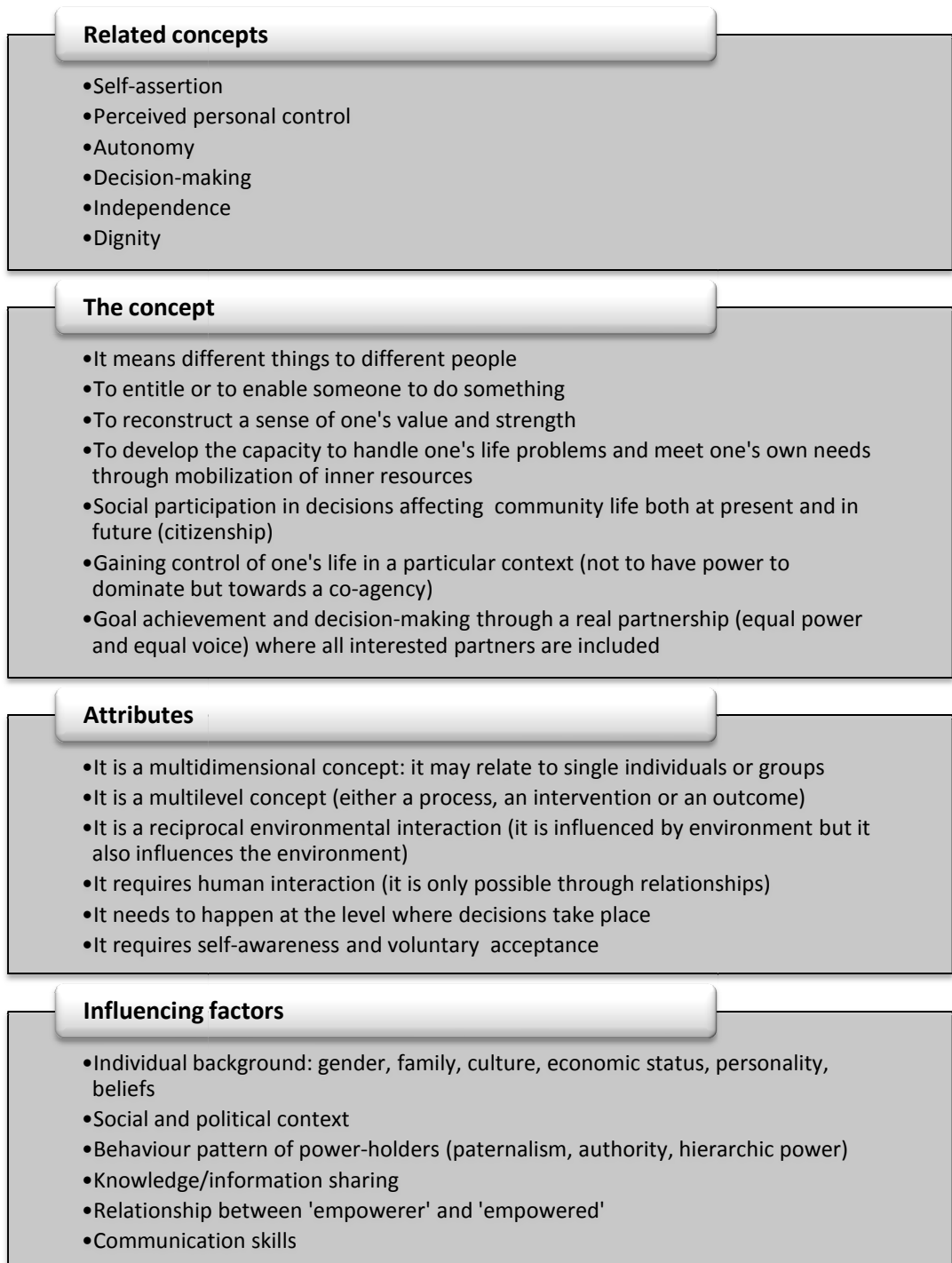
Thus, it is possible to state that to empower older people means to give them a voice to participate either in health care or in society making a positive contribution to enhancing the dignity to which they are entitled (Reed and McCormack, 2007), and that this fits appropriately into nursing care and concerns, as “empowerment is an ongoing process of change (...) and can be assessed and achieved through nursing knowledge” (Shearer and Reed, 2004). However, the concept of empowerment needs to be explored in the nursing field, developing the necessary knowledge to move on and help hospitalized older patients to come out from silence and to find a voice.

As Stanley (2006) states, some leadership may be needed in nursing to help others (nurses and patients) to feel self-confident, motivated to participate in care, “sowing a seed somewhere and letting others taking the lead”. This first step may be through knowledge development and dissemination; namely, exploring what the meaning of empowerment is in specific contexts such as, acute care, in specific populations such as, older patients, encompassing professionals’ and patients’ points of view.

Furthermore, the concept analysis regarding older people is mainly based on nursing homes, home care or long term care settings, rather than on acute care units (Ambrogi, 1989, Collopy, Dubler and Zuckerman, 1990, Lidz, Fischer and Arnold, 1992, Agish, 1993, Jecker, 1993, Post, 1994, Meddaugh and Peterson, 1997, Mullins, *et al.*, 1998, Shiu, 2001, Hellström and Sarvimäki, 2007, Scourfield, 2007). Moreover, previous studies of hospitalization have relied on professional opinion, neglecting the patients’ point of view (Rentsch, *et al.*, 2003, Hellström and Sarvimäki, 2007).

Thus, it may be argued that empowerment is a complex and interactive concept, closely related to other core concepts having a wide range of attributes and influencing factors, as summarized in Figure 3.

Figure 3 – Concept of empowerment summarized



Therefore, considering that power is shared and that empowerment is a positive movement “where power is taken over and given away” (Aoki, 2002) many questions may be raised:

- From whom is it taken?
- How can it be shared?
- How does the power “owner” start the movement? What are his/her motivations?
- How can anyone claim the power he/she needs?
- How is autonomy experienced by older people in an acute hospital setting?
- How do older patients cope with the decision-making process?
- How do nurses experience older people’s demand for empowerment?

Many other questions could be asked as linked to other core concepts namely autonomy and decision-making, as it will be explored subsequently.

## **2.2. Autonomy**

The origin of the concept of autonomy comes from ancient Greece: *autonomos* or *autonomia* are Greek words that mean self-government, encompassing the quality or state of being self-regulated, the right and the freedom to do it and moral independence (Ballou, 1998). The first references to the concept relate to political issues, in the 5<sup>th</sup> century BC, referring to “a state that is free to determine the norms by which it wants to live”, in opposition to the despotism of stronger countries (Ballou, 1998). After this, the concept developed widely, keeping the notion of having freedom to carry out self-governance vis-à-vis one’s system of laws or principles, encompassing the attributes of ability, capacity, competence, decision-making and critical reflection and expressed through actions.



Autonomy is a widely used but loosely defined concept in nursing (Davies, Ellis and Laker, 2000), closely related to well-being and empowerment and involves “control over one’s life, opportunities to make choices, and feeling comfortable about developing and using one’s personal resources” (Heathcote, 2000). Furthermore, despite individual and social or cultural variations, it is a human concern in the ageing process.

The focus of this concept is not only on “being able to do” but also on “being able to decide what to do” and, thus, leads to questions directly related to the freedom to choose and to the empowerment process. In a European cross-national study with older citizens, particularly involving Italy and the UK, autonomy emerged as a vital concern. Participants even expressed that “it is better to die than to lose one’s autonomy” which means to retain control over one’s life, “retaining one’s faculties, one’s peace of mind, one’s health and interest in the world” (Heathcote, 2000). Nevertheless, autonomy has a particular meaning and results in each particular context, depending on individual, political, social and cultural differences (Ballou, 1998).

Autonomy is a core issue in the care of older people and a basic ethical value, where conditions of frailty and dependence on caregivers can threaten self-determination, dignity, and quality of life. However, in spite of being a frequently-used term in nursing care, the concept of autonomy is often considered as the ability to achieve high scores on some task performance measurement scales (Cabete, 2001, Boyle, 2004, Cabete, 2005b, Calnan, Badcott and Woolhead, 2006, Boyle, 2008).

Nevertheless, in the past decades, discussion of the concept of autonomy has gained considerable relevance, following the increasing number of dependent older people (Folstein, Folstein and McHugh, 1975, Collopy, Dubler and Zuckerman, 1990, Faulkner, 2001a). Some reasons that furthered such discussion are:

- The ageing process of individuals and societies;
- The increasing cost of medical technology, pushing “early-as-possible” discharge of older patients;
- The growing rates of chronic illness, with consequent growing prevalence of individuals with variable dependency levels.

However, although autonomy and dependency are related, these are not simply opposite concepts: autonomy is not the inverse ratio of one’s dependency level. Nonetheless, in discussions about promoting autonomy, it is often used (even in the literature) as synonymous with promoting independence regarding task performance, namely activities of daily living. Thus, to avoid this trap, it is necessary to clarify the concept of autonomy vis-à-vis independence.

According to common sense, a dependent is someone who depends on another for material support (food, clothing, money...), especially when this is not normal or necessary. It is the quality or state of being influenced, controlled or materially supported by another person. It is to need someone (or something) to accomplish one’s daily living activities in order to survive or be successful (Procter, 1981, Wehmeier, 2005).

The extended concept of dependency is related to “doing things” with help, and thus the opposite concept of independence (where there is no need of another’s help). The issue is not the decision, but the impairment: someone is unable to do something without the intervention of somebody or something. In other words, I may be unable to feed all by myself (I am dependent) but I may still be able to decide whether I want to eat and when (I am autonomous). Thus independence (the “all by myself” concept) is not necessarily synonymous with autonomy, as the focus of this concept is not on “to be able to do” but on “to be able to decide what to do”.

According to Doyal and Gough (cited in Boyle, 2008), autonomy is not only a universal human need but also a human right, essential for well-being and social participation and even necessary to avoid serious harm. The same authors identified two levels of autonomy: (1) freedom of agency (encompassing both freedom of choice and action) and (2) critical autonomy, i.e. the “opportunity to express both freedom of agency and political freedom”. Moreover, it is important to be aware that in order to be able to make informed choices and to accomplish these choices it is necessary that further than just allowing this freedom, it is also vital to give “material, educational and emotional resources to enable an individual to be autonomous” (Boyle, 2008). And this should be one of the aims of the empowerment movement: to search for the necessary resources to make self-determination possible, as autonomy encompasses the freedom, the ability, and the willingness (Cabete, 2005b). For example, in the common and apparently simple decision of whether to stay in bed or to sit in a chair, the patient needs to know that the possibility exists, what the benefits or potential harms of each possibility are and she or he must be reassured that she or he will not be left in that chair for hours. Thus, it is necessary to give the freedom of choice, the resources, the information, and the physical and emotional support.

According to Doyal and Gough (2008), there are three determinants of autonomy: (1) the understanding that an individual has about herself/himself and her/his condition, according to her/his culture, (2) the psychological capacity to formulate options and (3) the objective opportunities available. The challenges to autonomy are present in each one of these dimensions; firstly, because society has developed an image of older people that includes dependency and submission; thus, it is expected that older people rely on others’ decisions. It is very common in the current (Portuguese) language to listen to the expression “oldies become children again”. Sadly, this (sup)position is often adopted by older people as well. Thus, dependency stereotypes must be questioned, discussed and changed as this paternalistic assumption does serious harm to one’s autonomy.

The second determinant of autonomy, psychological capacity, leads to the discussion about “who is able to decide?” In other words, it is necessary to question the assumption that only mentally unimpaired people (emotionally or cognitively) will be able to be autonomous and that it is not possible to work towards the respect of someone’s autonomy if he (or she) is in coma or under anaesthesia, or depressed, or suffering dementia. Arguably, in mentally healthy persons, it is easy to understand and to achieve autonomy. However, even in situations (either acute or chronic) where some impairment is present, it is vital to avoid people’s being neglected or ignored; and in the ageing process sometimes some impairment may arise. Furthermore, in hospitalization, physical and physiological constraints are ever-present.

Thus, it is a challenge to health professionals to search for the opportunities to promote individuals’ autonomy, instead of assuming themselves as the ones entitled to make choices (Hansen, *et al.*, 2002, Cabete, 2005b, Silva, 2006). Moreover, sometimes patients and professionals have different perceptions: on the one hand, patients may passively assume that professionals should decide and, on the other hand, professionals do not adequately assess patients’ needs or skills (Hansen *et al.*, 2002).

Regarding the opportunities to make choices, it is clear that it is necessary to analyse the real possibilities, in a specific environment: in long-term or acute care, at home or in hospital, the possibilities may be different. However, the opportunities for exercising autonomy also rely on the human environment. Nonetheless, health professionals often welcome patients’ autonomy of action but do not encourage decisional autonomy (Boyle, 2004, Zoffmann and Lauritzen, 2006, Boyle, 2008). Hence, it is vital to discuss the concept of autonomy in nursing care, particularly in the care of older people, as it is an important issue in enhancing individuals’ dignity (Griffin-Heslin, 2005, Calnan, Badcott and Woolhead, 2006).

The question of autonomy began to emerge in nursing care of older people in the context of long-term care, at home or in nursing homes, mainly connected with the assessment of daily living performance abilities. According to Post (1994), although the boom in nursing homes took place in the 1950s, only in the mid-1980s had some attention to the issue of autonomy begun to appear in the literature. Moreover, it was only in the early 1990s that this issue gained some consistency, when regulations came out specifying that residents in nursing homes had “rights to a dignified existence and self determination” (Roth and Harrison, 1994). However, at that point, the emphasis was on a medical view of autonomy, focused on performing tasks, rather than respecting an elder’s decision-making abilities (Post, 1994, Roth and Harrison, 1994). Nonetheless, it acknowledged the relevance of defining some standards to increase quality of care. Examples of this are either the efforts to minimize the use of physical and chemical restraints (sedatives or psychotropic drugs), or the condemnation of the systematic use of feeding tubes or even the statement that care should be provided (or at least directly supervised) by nurses. On the other hand, it is also stated that it is not only through legislation or regulation that autonomy is promoted in nursing homes but through a caring attitude “characterized by respect for human dignity and personal space, concern for others and a sincere valuing of the interdependency that must exist while continuing to affirm individual differences” (Roth and Harrison, 1994).

In the field of geriatric care, Jecker (1993) argues that autonomy is clearly connected with self-determination encompassing three levels of concepts:

- **“Autonomy as free action”**, meaning actions that are intentional and voluntary;
- **“Autonomy as effective deliberation”**, referring to choices that emanate from an understanding of available alternatives and their consequences,

and which finds expression in informed consent for significant medical treatments.

- **“Autonomy as consistency”**, focusing on the coherence of all decisions and actions reflecting past, present and future goals. Authors emphasize this dimension of autonomy because in chronic illness and long term settings the daily rituals and the ongoing relationships are the main determinants of autonomy erosion.

Thus the dimension of consistency may be the one that helps us to understand and help patients with acute or chronic mental impairment in order to keep their dignity and maximize patients’ participation in care: in other words, if nurses and families are aware of decisions made in the past, of patient’s usual behaviour or preferences, it will be easier to act in a coherent way according to patients’ background.

Moreover, research in geriatric settings alleges that nursing home residents and patients need an environment in which staff positively supports autonomous daily living. However, by analysing staff attitudes towards older peoples’ autonomy, it is possible to see that passivity and cooperation with institutional orders is greatly encouraged (Lidz, Fischer and Arnold, 1992, Agish, 1993). There are many examples of staff attitudes opposing the patient’s autonomy (Jecker, 1993, Post, 1996):

- The privacy of patients is not respected: room doors are routinely open, staff enter without a warning, confidentiality is non-existent;
- Institutional and staff structures and proceedings are considered more important than an elder’s wish;
- Even when patients have closed doors, privacy with respect to space, property, body or information is poor;
- Physical restraints are often used rather than other solutions;

- Patients' requests are often denied or delayed.

Lidz, Fisher & Arnold (1992) strongly criticize the expected “elder’s sick role” in geriatric institutions “perhaps dedicated to their health and safety, but detrimental to their autonomy”. These institutions strip the patient of her or his private identity and impose hierarchical authority. There are no patient-directed activities, restrictions on contact with the outside world are imposed and permission from staff for minor actions is required. We find different sources of restraints to autonomy: regulations, administration and staff behaviour in an environment with “as many trappings as hospitals”(Lidz, Fischer and Arnold, 1992).

Ambrogi (1989) states that “apart from criminal detention or involuntary civil commitment, few circumstances in American life impinge on individuality and personal autonomy as much as residence in a nursing home”. Ambrogi’s work points to examples of disempowerment: residents are ignored even in the admission process, the contract is signed by “a responsible party” without a formal delegation, “almost all agreements and regulations fail at the most basic level of readability and comprehensibility”. There is a lack of information about residents’ rights and the informed consent is ignored or presumed by institutions or staff.

Over 20 years since Ambrogi’s (1989) work, numerous studies still state that autonomy in geriatric environments is more rhetoric than reality and patients’ active participation in decision-making often undervalued or even ignored (Davies, Ellis and Laker, 2000, Lothian and Philp, 2001, Nordgren and Fridlund, 2001, Paterson, 2001, Hansen *et al.*, 2002, Boyle, 2004, Griffin-Heslin, 2005, Charles, *et al.*, 2006, Entwistle and Watt, 2006, Montori, Gafni and Charles, 2006, Murray, Charles and Gafni, 2006, Zoffmann and Lauritzen, 2006, Zoffmann, Harder and Kirkevold, 2008). Even when patients report partial satisfaction with care, some studies point to a lack of agreement between nurses and patients regarding needs assessment, despite nurses’ assertions that autonomy is a very

important subject in geriatric care as evidenced in a Scottish study conducted in 15 continuing care units and 7 private nursing homes, involving patients and nurses (Scott, *et al.*, 2003):

- Regarding information-giving about treatments, length of stay, risks of treatment, pain relief, names and doses of medication, and how to support bowel and bladder functioning – only 15% of patients reported that nurses had always given information but 54% of nurses stated that the information was always given;
- Nurses gave more information to patients having higher levels of education;
- None of the patients reported that the opportunity to participate in decisions was ever given (e.g. in pain relief management), while 20% of nurses stated that the opportunity was always given;
- Regarding informed consent to treatments or examination: for example, 20% of patients and 60% of nurses stated that informed consent was sought before taking blood tests.

Thus, it is clear that nurses must self-assess their practice and rethink what autonomy means to patients in order to act accordingly.

However, we must not be limited to a concept of autonomy that mirrors only the needs of unimpaired people trapped by their passivity and by institutional power and practices. These considerations lead us to argue that the individual patient's autonomy overrules institutional interests, family's opinions or professional convenience (Collopy, Dubler and Zuckerman, 1990). Being a concept related to the decision-making processes, this brings us to questions directly related to the freedom to choose and to the empowerment process.

The concept of autonomy in the context of acute care started to gain relevance nearly four decades ago, as an ethical value centred on patient competency and



self-determination, connected to the development of high technology that required difficult decisions related to maintenance of life in complex situations. Hence the discussion focused on patient's consent or refusal to medical procedures, the patient being 'the necessary and sufficient decision-maker' (Collopy, Dubler and Zuckerman, 1990). However, according to this point of view 'patients and caregivers confront each other unequally' as 'patients are displaced from their daily lives into an institutionalized environment' where health professionals are highly specialized and patients depend on their willingness to explain procedures, risks and benefits (Collopy, Dubler and Zuckerman, 1990). Hence patients' autonomy relies on their independence of judgment and decisional capacity, being 'defined in terms of patient's right to make decisions about medical treatment, free from coercion and in the light of adequate information'(Collopy, Dubler and Zuckerman, 1990).

However, the ageing process, along with the increasing burden of chronic conditions, challenge this model as the decisions needed are not only 'life-and-death decisions', Conversely, many ethical conflicts are more likely to be related to activities of daily living in which patients may be unable to execute but able to make decisions. Thus 'in the minds of caregivers inability of clients to *do* is seen as inability to *decide*' and 'the same assumption may be also internalized by the elderly themselves' (Collopy, Dubler and Zuckerman, 1990). The same authors state that it is necessary to take into consideration that executional incapacity should not be confused with decisional incapacity.

The distinction between decisional and executional autonomy is one of the key points brought up by Collopy (1988a) in the exploration of the concept of autonomy in long term care. Decisional autonomy encompasses 'the ability and the freedom to make decisions without external coercion or restraint' while executional autonomy consists of 'the ability and the freedom to act on this decisional autonomy' (Collopy, 1988a). Thus autonomy is a broader concept and in its full extent includes both dimensions, but it cannot be assumed that if one is

diminished the other one is also limited. Conversely, 'loss of execution argues for greater protections for decisional autonomy, precisely because the physically dependent elderly are increasingly vulnerable to external coercion' (Collopy, 1988a). Nonetheless other crucial clarifications in the concept of autonomy are discussed by the same author, namely related to the issues of delegation, competencies, and authenticity.

The issue of delegation is also a relevant matter in terms of understanding autonomy: it means that 'individuals may freely accept decisions and activities supplied for them by others' (Collopy, 1988a). Nonetheless this means that they give permission and that delegation is also acknowledged as a valid form of autonomy. And progressive dependency on others' agency may lead to increased vulnerability, particularly in a long term care environment. If delegation is not accepted as part of autonomy there is a risk of just considering one's direct action as valid autonomy. Furthermore 'in contexts fixated on direct autonomy, the older people must perform with high autonomy or else be relegated to the ranks of non-autonomous' (Collopy, 1988a). However, when older people's capacities decrease, autonomy may be challenged and the question of competent autonomy may be raised. Collopy (1988) defines competent autonomy as the 'choice or behavior that is informed, rationally defensible, and judgmentally effective in choosing appropriate means to desired ends'. However in some situations incapacity arrives and older people's choices may be unreasonable or even harmful. The key to maintain autonomy is to know when is reasonable for others to decide on patient's behalf. For that reason it is necessary to perform adequate assessment and to know patients' life and history, which leads to the topic of authenticity.

Authentic autonomy is defined as 'choices and behavior that are deeply in character, that flow from past moral career and ethical style, as well as from present values and immediate self-shaping' (Collopy, 1988a). Consequently to assess authenticity requires a deep knowledge of patients' background,

personality, past preferences, moral values as well as present motivations. Thus autonomy is also consistency over time and congruence with one's values.

Autonomy can be a source of many ethical dilemmas particularly under conditions of progressive dependency, principally if nurses understand autonomy only as the capacity to act and/or to make decisions. If physical impairment arrives, patients are often ignored as decision makers and if cognitive impairment arrives, nurses feel free to make decisions on patient's behalf. This is a dichotomist approach to the patient, underlining a body-mind separation instead of a patient-centred approach (McCormack, 2002). Working towards person-centred decision-making is a complex activity and becomes even harder in situations of cognitive loss as it requires adequate patient assessment (McCormack, 2001). Furthermore it challenges nurses' judgment of patients' competence or incompetence to be autonomous. For that reason, assessing patient's autonomy requires knowledge about 'the person of the voice' (McCormack, 2002). As Collopy (1988) also states, autonomy is related to congruence, authenticity and competency over the life span.

According to McCormack (2003), person-centred practice is essential to achieve older patient's autonomy, through a partnership based on a negotiated relationship. This means that nurses must acknowledge patient's right to participate in the decision-making process, i.e. 'whatever service is provided, the patient's right to be an active participant in his/her care program must be seen as central to a quality service' (McCormack, 1993). However, to achieve patient's autonomy in hospital environments is not an easy task and many constraints were identified like 'the dynamics of power and control, patients' access to knowledge, the impact of professional authority, the constraining nature of institutions and the effect of family and career on decision-making' (McCormack, 2003).

Patient centred practice is more than asking the patient what his or her preferences are, or to take note of his beliefs: it requires an authentic consciousness, i.e. taking

the person's life as a whole, to explore the meaning of life in order 'to maximize opportunities to growth through authentic decision-making, that is, decisions that are true to the person's life as a whole' (McCormack, 2003). Working towards patient centred care requires the acknowledgment that each person (both patients and nurses) bring a life experience to the situation of care and that the patient has the right to self-determination. The role of the nurse is to be a facilitator 'offering personal support and practical expertise, while enabling the patient to follow the path of their own choosing and on their own way'; it requires flexibility, mutuality, transparency, negotiation and sympathetic presence (McCormack, 2003). 'The nurse as a facilitator of an individual's authentic consciousness engages in a process of dynamic caring that maintains autonomy at a time when for many people, their sense of independence is under greatest threat' (McCormack, 2003).

There are few studies that explore older people's autonomy in hospital environments that encompass the patient's point of view. Nevertheless, from the examples given, it may be concluded that the landscape is not significantly different from that of nursing homes.

In a qualitative study with 17 patients in Sweden (7 patients over 65 years old), Nordgren and Fridlund (2001) report that patients' perceptions include trust in staff ( a feeling of security), accommodation to staff's authority, lack of knowledge of how to participate in decisions, and a feeling of powerlessness (struggling from a disadvantageous position, a feeling of not being believed, a feeling of not being involved, and a feeling of a lack of information and communication in the relationship with the staff). In this study, patients did not feel autonomous and expressed a compromised self-determination.

In a Canadian study McWilliam et al (1994) reported that the paternalism of professionals and a strong biomedical orientation translated into "lack of clarity about goals", seriously threatening the patient's autonomy in hospital,

independently of clinical condition. Nevertheless, patients having a positive mindset do not experience such harm. Ten years later, in the context of acute care for older people in the USA, Jacelon (2004) reported threats to autonomy related to the lack of informed consent for treatments, decisions made by carers and the “alien and inflexible hospital environment”. The author also underlines that, to hospitalized older patients, autonomy has two main dimensions: independence (the physical engagement in activities) and control (the ability to make decisions on one’s own behalf). Additionally, autonomy is a major concern to patients during hospitalization, particularly when they come close to discharge.

The autonomy and dignity of older people in health care settings are seriously threatened by staff attitudes and “healthcare professionals hold stereotypical, negative attitudes towards older people” (Lothian and Philp, 2001) because essential components of autonomy are not effectively addressed; for example, adequate information is not provided or opportunities to participate in decision-making are not given (Heathcote, 2000, Scott *et al.*, 2003, Calnan, Badcott and Woolhead, 2006) .

Nonetheless, the literature supports the evidence that there are positive outcomes from promoting the autonomy of older people, including higher levels of satisfaction with care, lower dependency levels and increased sense of personal control (Davies, Ellis and Laker, 2000, Lothian and Philp, 2001). Some possible interventions are pointed out:

- Offering choice in relation to daily activities;
- Providing adequate information about care and health conditions;
- Using understandable language;
- Asking for patients’ feedback relative to actions or care given;
- Demonstrating reciprocity in relationships;
- Protecting and respecting privacy;

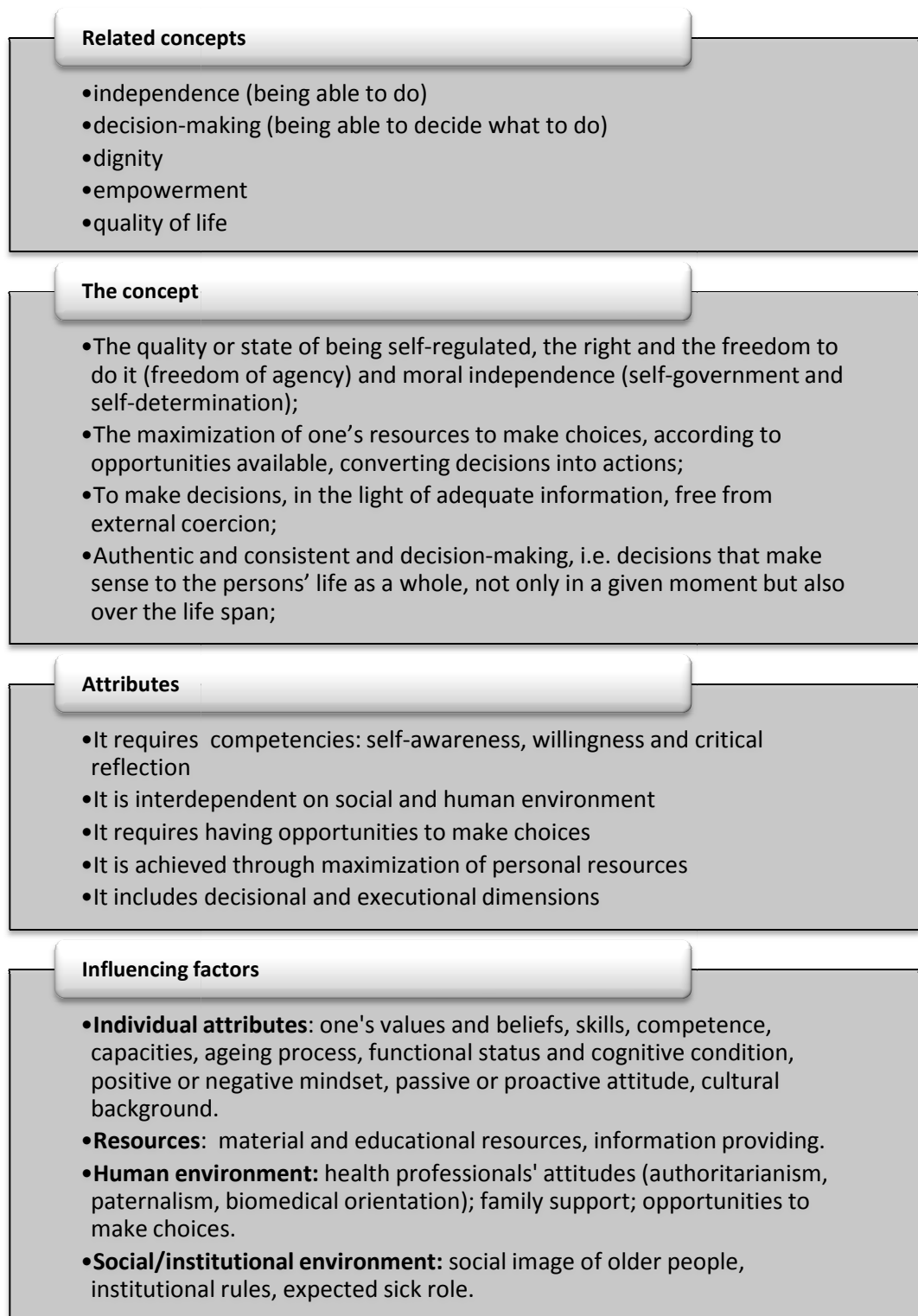
- Encouraging participation in care;
- Giving opportunity to participate in decisions;
- Addressing adequately cultural differences.

Moreover, it is important to acknowledge that the patient's mindset has a determinant role in overcoming threats and, thus, must be assessed and worked out as it is directly correlated to loss of autonomy: because if the mindset is a more positive mindset, there is less autonomy loss and if it is more negative, there is more autonomy loss (McWilliam *et al.*, 1994).

Thus, on the one hand, the literature supports the assertion that older people feel that personal autonomy is important and a significant contribution to a good quality of care. On the other hand, some passivity is often assumed by patients, possibly mirroring a "learned helplessness" induced by the staff's paternalistic behaviours (Faulkner, 2001a). Hence, patients must be aware of their right to participate in decisions regarding options of care and the way these decisions are carried out. Moreover, professionals must reflect on practice, analysing concepts, beliefs, behaviours, attitudes and looking for more effective action.

According to the learned helplessness theory (Seligman, 1975), when individuals experience events they cannot control they develop the expectation that future events will also be uncontrollable; this leads to three kinds of deficits: cognitive, emotional and motivational. On the other hand a positive response is also possible and was developed by Volpiccelli *et al.* (1983, cited in Faulkner, 2001) as the "learned mastery" theory. Thus, it means that if older people are exposed to situations where they are not allowed or encouraged to make decisions or actively participate in care, they will more likely depend physically and psychologically on caregivers and be less motivated to participate, with an increasingly passive attitude. The same happens in empowering or disempowering situations (Faulkner, 2001a).

Figure 4 – Concept of autonomy summarized



Thus, we may state that autonomy is a complex concept, relevant to nursing care and insufficiently explored in geriatric acute care. The studies point out that autonomy is linked with other concepts, namely independence, dignity and self-determination and that many factors influence its achievement, either environmental or individual ones, internal or external. And, despite its being easier to study the outcomes of the lack of autonomy, there is, nevertheless, sufficient support to state that autonomy over the lifespan plays a key role in quality of life, dignity and self-realisation. The core points from the literature reviewed are presented in Figure 4, organised around related concepts, external and internal determinants, and outcomes in order to systematize this information.

### **2.3. Decision-making**

If empowerment may be seen as “an enabling process to recognize one’s own strengths, abilities and resources to make changes increasing people’s awareness of their decision-making potential, working towards a mutual goal-setting” (Mapanga and Mapanga, 2004), the discussion about empowerment cannot be completed without addressing the issue of “decision-making”, a concept whose meaning, regardless of extensive debate, is not really clear to everyone, particularly that in the field of geriatric care (Montori, Gafni and Charles, 2006).

On the one hand, it is possible to say that in health care settings health professionals are the only ones entitled to decide. On the other hand, it is also arguable that the patient is the only one that has the right to make decisions about her or his own health. Moreover, it is also true that both professionals and patients rely on each other concerning information, treatment and outcomes. Thus, it is a matter of patient-professional relationships and how they come to a decision.



Regarding patient-professional relationships, it is necessary to refer to the work of Parsons (1951), which focused on the rights and duties of patients and doctors and described the sick role. In his book about social system theory, he describes the expected behaviours of patients and clinicians: the sick person is free from the usual social roles, is not accountable for his or her condition, should try to get well and should look for professionally competent help and cooperate with doctors, as they have the knowledge and the professional attitude to act for the patient's welfare. These are the outlines of the paternalistic model (Parsons, 1951).

According Charles *et al.* (1999), up until the 1980s, paternalism was “the most prevalent approach to treatment decision-making in North America (...) with physicians assuming the dominant role”. In the paternalistic model, it is assumed that physicians (or health professionals) have knowledge and the preferences regarding the best treatment or the best options for the patient, who is outside the decision-making process (Charles, Gafni and Whelan, 1997). Many assumptions may be found behind these attitudes: only physicians have clinical knowledge about illness and the clinical reasoning to select the best choice of treatment for their patients; they also have expertise and experience and, because of their professional concern with patients' welfare, physicians are entitled to decide and then inform the patient about the decision. The patient is expected to accept and adhere to the professional's prescriptions, giving consent to procedures. Moreover, these assumptions were supported by “professional codes of ethics which bound physicians to act in the best interest of their patients” (Charles, Gafni and Whelan, 1997, Gafni, Charles and Whelan, 1998, Charles, Gafni and Whelan, 1999).

However, the complexity of care, the numerous treatments for each disease and the associated risks of interventions, as well as consequences, challenged this almost almighty power. Also, the rise of the consumer's voice and cost and quality concerns pushed health care providers to listen to patients' opinions

(Charles, Gafni and Whelan, 1999). Thus, in the 1990's the patient-centred decision gained relevance and the informed decision (previously called consumerism) emerged as an alternative model. In the informed decision-making model, it is expected that clinicians give the patient all the clinical information available in order to allow that patient to choose treatment options. Thus, the decision that previously belonged exclusively to doctors moved to patients, as well as the responsibilities for failure and other consequences (Gafni, Charles and Whelan, 1998).

These two models seem to embody opposite positions:

Paternalism focuses on obligations; consumerism focuses on rights. Paternalism assumes the doctor is beneficent; consumerism assumes the doctor is self-centred. Paternalism implies the existence of trust; consumerism replaces trust with accountability. Paternalism assumes that principles of good medical care override individual treatment preferences; consumerism presumes that the patient's health care values dominate (Beisecker and Beisecker, 1993).

There are considerable similarities and differences between those two approaches, as both models are underpinned by a one-way information flow from clinicians toward patients and a single-person decision. What changes is the amount of information: in the paternalistic approach only a small amount of information is given to patients and in the informed decision model, physicians need to provide a considerable amount of information relevant to decision-making (Charles, Gafni and Whelan, 1999) .

Thus the shared decision-making model emerges as a more balanced situation where information flows in both directions (from patient to doctor and *vice-versa*). Discussion and decision regarding treatment options and preferences are shared as “in the shared model, both parties, through the deliberation process, work towards reaching an agreement and both parties have an investment in the ultimate decision made” (Charles, Gafni and Whelan, 1999).

The work of Charles et al (Charles, Gafni and Whelan, 1997, Gafni, Charles and Whelan, 1998, Charles, Gafni and Whelan, 1999, Charles *et al.*, 2006, Montori,

Gafni and Charles, 2006, Murray, Charles and Gafni, 2006) discussed broadly the concept of shared decision-making in the health care patient-staff relationship, clarifying different approaches to clinical decision-making namely, the paternalistic attitude, the informed model and the shared-decision-making model. Through this model, it is possible to answer the questions above: “who decides?” and “how decisions are made and on what information are they based?”

According to its authors, the main characteristics of the shared decision-making model are:

- It involves at least two participants (doctor and patient), but other parties may also be involved (family, other health professionals);
- Both parties (doctor and patient) commit themselves actively in the decision-making process;
- Information sharing is absolutely crucial;
- It requires negotiation and discussion of possibilities and preferences of patients and physicians;
- A decision is made and both parties agree on it.

Over the past years, this model has gained consistency and patient involvement in the decision-making process is now almost a condition of quality of care (Entwistle and Watt, 2006). Several organizations refer in their recommendations to the need to involve patients in decisions about their care. Some examples are, the General Medical Council of the UK, the Long Term Medical Conditions Alliance, and the US Preventive Services Task Force, all emphasizing that patients should be fully involved in decisions, should participate in their own care and that the “patient-clinician partnership is central to decision-making” (Entwistle and Watt, 2006). The Portuguese Health Ministry also supports empowerment as the most effective way to achieve health promotion and to manage chronic illness (Portugal, 2002).

However, “to be involved” is also something that may have different degrees or even different meanings, according to the effort made or even personal beliefs or physical or psychological condition. It is crucial to acknowledge a patient’s efforts and contributions, views and feelings about her or his role, the effectiveness of patient-clinician communication, clinicians’ efforts to establish a partnership, and clinicians’ views and feelings about their role. Moreover, it is important to recognise that the decision-making process is not just looking to a menu of choices but it encompasses:

- Recognition and clarification of a problem
- Identification of a potential solution
- Appraisal of potential solutions
- Selection of a course of action
- Implementation of a chosen course of action
- Evaluation of the solution adopted (Entwistle and Watt, 2006)

The shared decision-making model includes particularities according to different settings of care. Montori et al. discussed it in chronic conditions versus acute conditions (Montori, Gafni and Charles, 2006). Some differences include:

- In acute conditions, decisions usually take place in hospital or health care settings, decisions are urgent, often irreversible, and outcomes are immediate;
- In chronic conditions, decisions usually take place in a patient’s environment, having various windows of opportunity for decisions, which latter may be revisited and changed.

Thus, Montori et al state that shared decision-making requires a number of consecutive phases: “(1) establishing an ongoing partnership; (2) information exchange; (3) deliberating on options; (4) deciding and acting on the decision.”

Actually, the heart of the shared decision-making model in chronic conditions is the existence of “a healthy partnership between patient (and the patients’ family) and the clinician (and the rest of the healthcare team)” (Montori, Gafni and Charles, 2006).

Although it is not the purpose of this study to discuss decision-making models it is important to be aware of their implications for the empowerment process. However, it is not appropriate to accept or reject one particular model, as contexts and situations influence decisions (Gafni, Charles and Whelan, 1998). To make a decision in a life-threatening situation in an emergency room or in the follow up to a chronic condition are different situations. Even educational status or gender differences may influence the decision-making process; that is, it might not be realistic to expect that patients (even the informed ones) are “able to hold their own in negotiations with physicians (...) given the power, status and informational asymmetries” (Charles, Gafni and Whelan, 1999).

Regarding empowerment discussion, one may say that the paternalistic model leads to patients’ disempowerment, related to a complete lack of control of disease or treatments, or outcomes. However, the informed model may also lead to a forced empowerment, as many times patients do not want to make decisions. If the assumption is made that information given to patients leads to empowerment, it may not be automatically assumed that patients want to participate in treatment decision-making (Beisecker and Beisecker, 1993, Charles, Gafni and Whelan, 1999). An informed patient may prefer to decide her or himself, to delegate or to share the decision. And in the shared decision model one of the first steps is to find out if the patient wants to participate or not and, if the former, to provide that patient with the necessary information and support to do so.

Nonetheless, research has shown that through shared decision-making it is possible to promote patient empowerment and improve better health management

or even clinical outcomes (Messias, De Jong and McLoughlin, 2005, Trummer *et al.*, 2006, Zoffmann and Lauritzen, 2006, Corser, *et al.*, 2007). A study by Trummer *et al.* (2006), which included 198 patients undergoing cardiac surgery in an Austrian university hospital, demonstrated a reduced length of stay by one day, adjusted for intensive care levels (9.3 versus 8.1,  $p=.0004$ ), reduced incidence of post-surgery tachyarrhythmia (4% versus 18%,  $p=.027$ ) and improved ratings of patients', doctors' and nurses' subjective satisfaction with significant correlations between them ( $r=.734$ ,  $p=.004$ ). However, some authors acknowledge that empowerment through the shared decision model may be just rhetoric (Zoffmann and Lauritzen, 2006) "as major gaps have been found in clinical practice between the intention to involve patients in health planning and their actual involvement" (Zoffmann, Harder and Kirkevold, 2008). Moreover, it has been related that professionals like to keep the power over a patient's situation and prefer to perform tasks in which they may keep the control (Paterson, 2001, Christie, 2002, Anderson and Funnell, 2005). Thus, it is necessary to focus on professional/patient relationships, as through this it is possible to build patient empowerment.

According to Yedidia (2007), the doctor-patient relationship may be characterized in three models (1) the functionalist model – focusing on illness and medical expertise; (2) the patient-centred model – focusing on patient perspectives and autonomy; (3) the relationship-centred model – focusing on mutual understanding and collaboration; only the relationship-centred model addresses true empowerment issues. In this model, genuine engagement, trust and authenticity are fundamental to the development of a balanced relationship that will address patients' needs and promote empowerment.

However, all these models discuss the "doctor-patient" relationship and usually do not mention about nursing issues. Moreover, they focus on decisions related to diagnostic procedures, medical treatment options or disease control, mirroring a biomedical concern; and decisions regarding daily nursing care may be considered

as “less critical”, in a biomedical point of view. Of course, it is arguable that what is true of the doctors’ paternalistic attitude may also be said about nurses, as well as nursing advocacy models, vis-à-vis the patient-centred models (Vaartio, *et al.*, 2006, Llewellyn and Northway, 2008). However, this is a broader discussion as, if on the one hand it is suggested that “nursing advocacy contributes to patients’ self-determination, autonomy or empowerment, there are also arguments to the opposite effect, claiming that advocacy can be experienced as a paternalistic act” (Vaartio *et al.*, 2006).

Then again, it is necessary to analyse what nurses have in mind or why the paternalistic model still prevails. Nonetheless, the word “empowerment” is widely used in nursing care and literature, perhaps because it is politically correct and, thus, it is displayed everywhere (Anderson and Funnell, 2005, Brandon, 2005). There are some possible explanations of nurses’ resistance to adopting a new paradigm of care (Anderson and Funnell, 2005):

- During nurses’ education, socialization to a paradigm in use occurs, and it is very difficult to change it later in practice;
- Nurses’ education is grounded on acute illness and treatment-focused; even the approach to chronic illness is anchored in patient’s compliance to a treatment, a lifestyle or therapeutic regime considered (by nurses or doctors) as the most appropriate; nurses’ reasoning often is that “the patient has a problem and health professionals have a solution”; hence, patients must adhere to nurses’ instructions;
- Some nurses are sceptical about adopting an empowerment paradigm because they see it as “just another fashion” (the politically correct language), as more cosmetic than a real intervention, so it is not worth the effort to change;
- Nurses like to keep professional control of actions: they prefer to be responsible *for* patients, rather than responsible *to* patients;

- Some nurses believe that patient empowerment care will be more time consuming.

Even when nurses believe in shared decision-making, they repeatedly position themselves as experts, leaving only a narrow margin for patients' participation. Moreover, in the context of chronic disease nurses often assume the agreement of family caregivers, without even asking (Paterson, 2001). In her study, Paterson reports testimonies of 22 Canadian patients who were allegedly in an empowerment program of diabetes control; it was revealed that professionals listened to people but did not take into account the information. Nevertheless, changing the paradigm is possible, although it might take one generation to achieve it through reflection, discussion and education (Anderson and Funnell, 2005).

## **2.4. Hospitalization**

Regardless of age, to be hospitalized is a stressful event in anyone's life and it is known that to be confronted with disease and pain can have some consequences for daily living, quality of life and well-being. However, it looks as if older adults in hospital have to deal with more than mere disease. They have to face stereotypes of frailty and incapacity and they are often seen as "children, who don't know what the best is for themselves", or like persons without a will (Reich, 1997, Weinman, 1998, Cabete, 2001, Covinsky *et al.*, 2003, Cabete, 2005b). It seems that hospitalized older people are considered as persons unable to make decisions; neither about the activities of daily living, nor decisions concerning treatment and clinical proceedings: "Undoubtedly, when people are old, sick and dependent, they are in the ranks of the more vulnerable members of society" (Hoose, 1994).

Moreover, it looks as if hospitalization is an event that might contribute to unexpected outcomes as some studies have shown that at the time of discharge,



older people have lower levels of functional performance than they had before admission, and that the impact of hospitalization has negative effects, both on physical and psychological well-being, as patients often become passive consumers and cease to play an active part in the decision-making process (Wu *et al.*, 2000, Buffum, 2004, Beers, 2005). Additionally, the impact of hospitalization is not related to old people's disease (Creighton, 1995, Shedd, Kobokovich and Slattery, 1995, Gallo *et al.*, 2000, Cabete, 2005b) but to exposure to uncontrollable events: either neglecting people's right to information or forgetting to ask for consent (to daily activities or medical procedures), to more critical interactions, such as privacy invasion, disturbing patients while they are asleep, or even reprimands, negligence or physical restraints. All of these attitudes or behaviours have negative outcomes and happen without any patient intervention, leading to learned helplessness (Faulkner, 2001b) and increasing patient's dependence. Faulkner (2001b) also found in his study that older patients have less empowering care, possibly mirroring professionals' ageist stereotypes, and that empowering care is more likely to be provided by senior staff than by younger nurses or aides. Thus, hospitalization needs to be explored in order to understand the extent of its influence on older people's empowerment.

In his book *Prendre soin à l'hôpital*,<sup>4</sup> Hesbeen (2000) explores the paradoxes of hospital: built to take care of persons it has become the place where the interest is disease and where professionals are unable to deal with illness and people's emotions, namely, pain and suffering. Hospital practices are underpinned by a philosophy in which observation of disease is the centre of everything, where diagnostic procedures are more and more sophisticated, where more and more treatments are available, and where professionals state "if I do not see anything in

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<sup>4</sup> The Portuguese version is used and referenced.

your X-ray, you don't have anything", neglecting the human experience. This attitude develops an almighty medical power leading to an environment controlled by staff and out of the control of patients (who trust in science and often forget to claim their own right to being cared for like humans beings and not treated only as human machines). This kind of culture reinforces health professionals' paternalistic attitudes, strengthened by ethical codes of beneficence, thus contributing to the patient's disempowerment.

Nurses in hospital also behave in a way that often does not respect people's rights to information and personal attention and does not meet patients' expectations. Hesbeen (2000) describes some patients' expectations about nursing care:

- To have the kindness to introduce themselves;
- To explain all treatments and expected outcomes;
- To take the necessary time to talk to patients and give the required explanations;
- To show an open mind, welcoming the patient's queries;
- Not to lie about pain or discomfort that any treatment might cause;
- To give information about the care schedule;
- To explain to families how they may cooperate;
- To be coherent in information;
- To answer the patient's requests at a short delay;
- To keep continuity of care and avoid excessive staff rotation;
- To give information about possible consequences of the illness, as well as treatment consequences, not leaving patients unaware of their situation;
- To have effective staff communication to avoid patients' having to repeat over and over the same information;

- To listen to patients effectively and demonstrate genuine interest towards their worries and problems, without minimizing them;
- To be reliable, trustworthy, respectful;
- To respect the patient's rights, autonomy, dignity, privacy, values and beliefs;
- To accept patients as they are.

Without ever using the word “empowerment”, I would say that every one of these expectations is directly related to it: hospital patients have a strong desire to be empowered. Moreover, patients' testimonies often reveal a situation directly opposed to that of empowerment: “what really causes me suffering are nurses' coldness, technicians' indifference, noise, lights, uncomfortable bed... they do not care (...) they whisper incompressible things between them and even when they coldly shake our hand they talk as we weren't there” (Hesbeen, 2000). Moreover, staff makes patients feel that they, the staff, own the territory: not knocking on the door, not asking for permission to touch a patient's belongings, uncovering a patient's body as if it was public property, are more than just an invasion of privacy. For these and other examples Hesbeen (2000) even uses the expression “hospital violence”. And all of these attitudes and behaviours are the opposite of nursing principles and philosophy (Nightingale, 1969, Henderson, 1978, K  rouac *et al.*, 1994, Colli  re, 1996, Watson, 1999, Hesbeen, 2000, Colli  re, 2001, Hesbeen, 2001, Rispail, 2003, Hesbeen, 2004, Honor  , 2004, Henderson, 2007).

Thus, it seems that hospital power is stronger than patients' rights and aspirations, as well as nursing values and principles. Biomedical philosophy and hierarchic authority, professional power and deeply-imprinted routines have the control, not humanistic values nor a democratic practice of shared citizenship. On the one hand, nurses learn and claim that the true essence of the nursing profession is to help individuals to find a meaningful way of living in their unique context and

situation, independently of their bodies' condition but, on the other hand, they still practise according to a biomedical culture (Hesbeen, 2004).

Patients of all ages are hardly listened to in hospital: as an example of this, in a cross-sectional study involving 477 patients admitted to the university hospitals in Geneva, Switzerland, only 8% stated that they took part in admission decisions (Rentsch *et al.*, 2003). Moreover, there were significant differences between patients and staff regarding the reasons and appropriateness of hospital stay and discharge plan discussion. Furthermore, in older people, the situation becomes even more critical. For example, regarding older people's hospitalization and discharge, Coffey (2006) conducted a systematic literature review, calling attention to some core concerns:

- There are difficulties in discharging older people from hospital; namely, because of decreased functionality;
- Better outcomes are achieved through advanced practice nursing, with patient-centred care encompassing patients' participation in decision-making;
- Exploring patient's perceptions of hospitalization and discharge, it was found that there were significant gaps in information, no involvement in decision-making, with more than half of the patients stating that they were not consulted about their discharge nor was any specific information given about care;
- Older patients' concerns include difficulties in getting help, and independence loss;
- Older people's adjustment strategies to hospitalization identified were positive resignation or passive acceptance;
- Older patients whose families or friends became involved in care were more likely to participate in decision-making;

- Some patients experience powerlessness owing to the staff's centre of attention being on medical condition and administrative procedures;
- It is important to give patients time and opportunities to express their concerns;
- Older people feel that health professionals fail to understand the complexity of an older patient's needs during hospitalization, needs which go far beyond the physical or clinical dimensions.

Moreover, the negative physical impact of hospitalization is demonstrated: the research conducted by Covinsky et al (2003) in the USA shows that up to 35% of older patients are discharged with poorer functional condition than their baseline assessment and that the oldest patients are more likely to develop new functional deficits during hospitalization, due to recovering difficulties; additionally, 43% of patients admitted decrease their functional scores during hospitalization. Also, in Taiwan, Shyu and Lee (2002) state that the decreased functional performance resulting from older people's hospitalization (self-care ability, tubes remaining after discharge, and consciousness level) is a strong predictor of institutional placement (nursing home or other institution). Thus, keeping functional performance is a core concern to allow older people to return home.

It is significant that in the literature a common research topic regarding older people's hospitalization is functionality and discharge issues: thus keeping the focus on biomedical and management concerns. However, there is also evidence to show that promoting empowerment, autonomy and shared decision-making will improve both physical and emotional conditions. Thus, it is necessary to get patients actively involved in the hospitalization process as decision makers. Also, Roberts (2002) demonstrated that older people are able and willing to assume an active role in their health process, namely, regarding discharge, and that partnership is possible between older patients and health professionals, leading to better outcomes: namely, patient satisfaction and adjustment to health conditions.

Therefore, it is necessary to explore empowerment and autonomy in order to draw professionals' attention to this issue. The research of Jacelon (2004) explores the issue of autonomy, finding that it is an ever-present concern of older people during all processes (immediate pre and post-hospitalization periods included), becoming the most relevant concern in the last phase (that is, as homecoming draws near). Describing the acute hospitalization event, encompassing nurses' and patients' points of view, despite its being a study with a small number of participants, this researcher's findings make good sense and some key points are really striking:

**Prior to being hospitalized:**

- Patients had a routine and controlled their own environment;
- Patients made the decision (perhaps with the family's help) to go to the hospital;
- On admission to hospital, older people freely suspend their autonomy and rely on health professionals' care;

**During the initial stage of hospitalization (stabilization period):**

- Patients are physically dependent;
- Patients willingly give up control for the security of being in the best place to be;
- Hospital routine imposes activity restrictions;
- Patients are too ill to wish for much independence;
- The individual's routine is taken away;
- Autonomy concerns are surpassed by health improvement worries.

**During the second stage of hospitalization (repairing phase):**

- Patients start to feel more confident and want to regain control over their own routine;
- Patients want professionals to leave them “to do things their own way” and want information to know what they might do to improve their condition;
- Patients feel the lack of control of their situation and want to recover autonomy and participate in decision-making;

#### **During the last stage of hospitalization (reintegrating phase)**

- The health crisis is stabilized or solved and going home comes near;
- Patients want to regain full control of daily routines and to participate in decisions;
- Patients should participate in the discharge plan;
- There are worries about not being able to reassume self-care responsibilities at home;
- Patients want to know what medication they take, why, the doses, and schedules;
- Strategies patients used during this stage include: worrying, maintaining health, taking action and taking responsibility;

#### **Post-hospital stages**

- Some support might be necessary until previous independence is recovered or there is a sufficient level to perform adequately;
- Autonomy increased as health continued to improve.

The main conclusions of this study point to patients’ ability to influence the course of hospitalization and to autonomy being a main concern during

hospitalization, particularly near discharge. Also, patients considered two main dimensions of autonomy: independence and control.

Hence, older patients must not be seen as care recipients, as they also want to participate in care and in decision-making despite, on some occasions, assuming passive roles, as they rely on professionals' competence and accept medical power.

Regarding patients' willingness to participate, it is also significant to explore patients' attitudes and perspectives as having a positive (or negative) influence on health experiences and outcomes, as well as patients' beliefs about their responsibility in controlling the situation. Researchers have found that having a positive mindset, as well as a sense of purpose in life, affects not only the emotional resources to cope with stress but also relationships with health professionals, willingness to fight disease or to take control of the situation, resilience, and patients' attitudes towards dependence on others (McWilliam *et al.*, 1994, Faulkner, 2001a, Silva, 2006). Keeping empowerment and autonomy (as agency and as control over agency) is directly related to a positive mindset: as the more positive old people are, the more they are able to keep autonomy. The inverse is also true: the more negative older patients are, the more disempowered and dependent they become (McWilliam *et al.*, 1994). A patient's attitude towards life events influences not that only that patient's own behaviours but also health professionals' attitudes and behaviours.

Hence it is relevant to take into account patients' mindset, as well as their willingness to control the situation. As stated previously, hospitalization represents an exposure to many factors that are out of the control of patients and may induce a learned helplessness leading to disempowerment.

However, patients' attitudes towards external challenges are also related to one's beliefs of being able (or not) to influence external challenges. The Locus of Control theory gives us a possible understanding of this interaction. The construct



of locus of control (widely used in the field of Health Psychology) was developed by Rotter in the field of the Social Learning Theory (Rotter, 1954, 1975, 1990) and expanded by Levenson (Levenson, 1973, 1974). It states that individuals may believe that life is controlled either by internal forces they can control or by forces outside themselves.

People with an internal locus of control tend to analyse circumstances searching for ways to influence them. They believe that health is a result of their choices, generally enjoying better health conditions, higher levels of life satisfaction, and smaller levels of stress and will be more likely feel powerful.

Conversely, people with external locus of control feel they are at the mercy of circumstances that other powerful persons control (e.g. the doctor, God) or just external or accidental factors (e.g. luck, chance, destiny). They are more likely to feel powerless and to suffer from higher levels of stress, depression, poorer health conditions and less life satisfaction.

Despite the term being widely used in health literature, namely in adherence to treatments or to healthy lifestyles, there is not much exploration of this in the field of geriatric acute care. A review of health databases (CINAHL with Full Text, Science Direct, ProQuest Nursing Journals, ASSIA, Web of Knowledge and Wiley InterScience) did not return any result for the combined key terms of locus of control, empowerment and older people in hospital environments.

The studies mentioned previously referred to the issues of perceived control in nursing home environments (Shiu, 2001) or to adherence to treatment in chronic disease (Nielsen *et al.*, 2008, Rimmer and Rowland, 2008, Zoffmann, Harder and Kirkevold, 2008) and claim that positive perceptions of control are predictors of better health outcomes. Nevertheless, the study by Shaw *et al.* (2003) demonstrated that internal locus of control was also related to better physical outcomes in older patients undergoing surgery for fractured neck of the femur.

Once more, the focus is on measurement of physical outcomes, and this is not the purpose of this research.

Hence, there are many related concepts and factors influencing patients' lived experience of hospitalization and, despite not being broadly explored in the literature, locus of control may be one question to have in mind for in-depth discussion.

## **2.5. In brief**

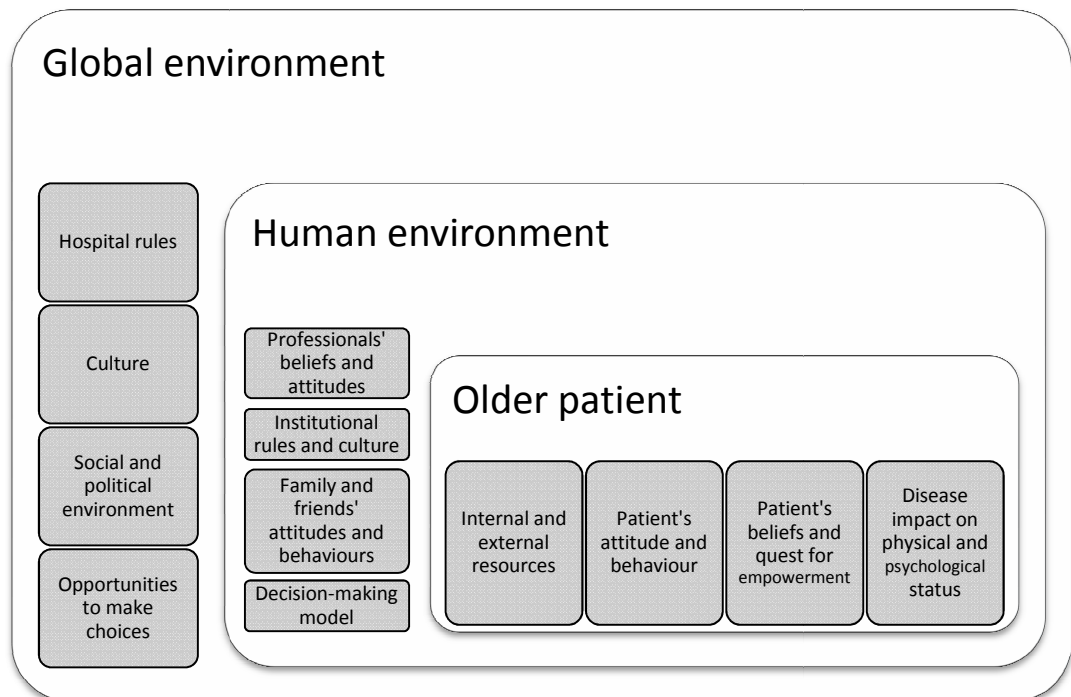
There are considerable challenges in an ageing society: to adjust health care to an old population is just one of many concerns. Hence, nursing care needs to be redefined to address older people's needs: keeping older people's autonomy and promoting empowerment need to be a focus for action. However, to keep or to promote autonomy seems to be more present in nurses' discourse than in their practice. Moreover, little attention has been given to acute geriatric care as most literature focuses on nursing homes or on long-term care facilities.

Besides, each person's autonomy and empowerment depends on personal resources, beliefs, previous experiences, culture, education, access to health care, human environment, social and economic conditions, as well as policies, just to name a few. These are all interwoven variables, each one influencing all the others and it is impossible to isolate autonomy and the concept of empowerment from an endless range of influences. And hospital environment is just one more, encompassing many others.

In Figure 5, some core influencing variables arising from the literature review are summarised: some related to patients and their resources, others as part of human or global environment. However, even if a graphic representation helps to show an instantaneous approach to this issue, the variables are impossible to split and

store tidily in different drawers, as they intersect one another in complex and dynamic ways.

Figure 5 – Influencing variables of older people’s hospitalization



Hence, through a review of the literature, it is possible to support the idea that autonomy and empowerment are core subjects in health care, particularly in the field of care for older people. Nonetheless, it is also clear that there is a gap regarding the exploration of those concepts, particularly in the context of acute care for older people. As far as the autonomy concept is concerned, its exploration in the field of geriatric care is quite limited to long-term care, either at home or in residential care. In addition, when the concept is explored in the hospital context, it is mostly focused on functional performance assessment towards discharge.

Furthermore, the literature on the empowering of older people through nursing care is scarce, almost non-existent in the context of acute care. Besides this, most studies rely predominantly on health professionals’ opinions, neglecting older

people's points of view. Hence, my motivation to undertake this research emerged from the conviction that there was a need to develop these concepts, particularly by including the older person's point of view, which is, above all, a way to give voice to patients and, by doing so, to contribute to older people's empowerment.

Therefore, the aim of this study is **to explore the concept of autonomy and the empowerment process in hospitalized older people** in order to answer the question: **How do nurses and older people experience autonomy and the empowerment process in hospital?**

In this way, the study seeks:

- To explore nurses' and older people's concepts of autonomy and empowerment of hospitalized older people;
- To identify the role of nurses in the negative impact of hospitalization on older people;
- To explore ways to improve autonomy and empowerment of hospitalized older people through nursing care.

Hence, methodological issues will be discussed in the next chapter in order to explain how it was planned to reach a comprehensive understanding of the concepts of autonomy and empowerment in a particular context (hospital acute care in Portugal) in a specific population (older people) encompassing patients' and nurses' points of view.

### **3. METHODOLOGY**

The focus of this research is on the process of empowerment and the autonomy of hospitalized older people, encompassing patients' and nurses' experiences; trying to describe, analyse and interpret the meaning of events, confronting points of view and finding links. Thus, the research relies on people's experiences of a real life event and attempts to develop a refreshed and contextualised perspective of empowerment in an acute care setting. Hence, the core issue is to answer the question: "How do nurses and older people experience autonomy and the empowerment process in hospital?"

Choosing a research design is a core issue in answering a research question. Even if the perfect methodology does not exist, the endeavour is to find the one most adequate to fit the research aim. All research strategies have strengths and weaknesses, possibilities and limitations and no one can be considered better than others (Fortin, 1999).

Owing to the research question, a phenomenological approach has been chosen because the purpose of the study is to understand (and not to measure) lived experience and its meaning in a situational context (Todres and Wheeler, 2001, Streubert and Carpenter, 2002, Kleiman, 2004).

As a data collecting strategy, a biographic work was undertaken with patients and nurses. Subsequently, hermeneutic analysis was carried out to achieve insight into the phenomenon.

Thus, in the following sections, an attempt will be made to highlight the rationale of phenomenology and the use of hermeneutics in nursing research, as well as the foundations of the use of life histories in research and education. The study design will be presented, as well as its ethical implications.

### **3.1. Phenomenology**

As stated by Cohen et al (2000, p. 3) phenomenological research is used to answer questions of meaning and “is useful when the task is to understand an experience as it is understood by those who are having it”. Moreover, phenomenology leads us wherever our informants take us. In the present study, I want to raise the issue of empowerment in an acute care geriatric setting, offering a renewed perspective encompassing nurses’ and patients’ experience and interpretation.

Phenomenology is a way to knowledge and may be considered a philosophy, a methodology and a method (Byrne, 2001). To phenomenologist researchers, knowledge and understanding are embedded in the everyday world and cannot be reduced to numbers or statistics and “truth and understanding emerge from people’s life experiences” (Byrne, 2001). Using Kant’s distinction between “noumena” and “phenomena”, in other words, the “things in themselves” or the “experience of the things” (Cohen, Kahn and Steeves, 2000, p. 3), this study does not focus exclusively on empowerment, but explores nurses’ and patients’ experiences of empowerment.

Patients’ understanding is crucial, as nurses can only meet patients’ needs to the extent of their knowledge of patients’ experiences (Nightingale, 1969). Real nursing care is only possible if nurses are aware of their own beliefs.

Furthermore, the purpose of this research is to describe and analyse experience, not to control it: we cannot control hospitalization or its impact on participants’ real life. Also, it is impossible to isolate all variables or possible contextual influences on human experience. For example, it is not possible to separate variables and influences such as hospitalization, all hospital rules and practices, the cultural and social background of staff and patients, and an individual’s beliefs and fears. All variables are interwoven as in a fabric. Boundaries, either between variables or their context, are impossible to draw. Hence, phenomenological

research is a method to understand complex human experience in a particular context, this present study aiming to understand the experience of autonomy and empowerment of older people in the context of acute hospital care. Moreover, this study focuses on processes. Autonomy and empowerment are not statuses, but processes resulting from a challenging balance between the person and her or his environment, criss-crossed by an uncountable range of influences. In this research, I had no control over events (nor did I desire it). My goal was to understand contemporary and complex social phenomena within a real-life context.

Phenomenology is considered as a way to search for meaning: the meaning of things, of events, of a phenomenon, for those who experience these. Its focus is not on a deductive exploration of an object or a situation:

But rather a method for investigating and describing the presence of any phenomenon given to conscientiousness, precisely as it is given or experienced, in terms of meaning that the phenomenon has for those who experience it (Kleiman, 2004 citing Giorgi, 2003).

There are, essentially, two main phenomenological methods: descriptive (transcendental or psychological) and interpretative (hermeneutic). In the descriptive method, the researcher needs an attentive openness to listen to participants' descriptions of the phenomenon. Then, it is necessary to look for the essence of the text in order to describe it. Subsequently, "the researcher articulates a structure of the phenomenon of interest constituted by the discovered essential meanings and their interrelationships" (Kleiman, 2004). The outcome is a structured description of the phenomenon.

The interpretative method aims to transpose to language an insight of the phenomenon. The researcher assumes an attentive attitude but the purpose is to come to an understanding of the unique meaning and significance. The goal is to develop a strong and insightful text, representing the phenomenon as experienced by the subjects (Kleiman, 2004). In any case, to describe or to interpret a phenomenon according to someone's experience relies on his or her willingness to

tell his or her story in relation to a specific issue, since the nature of lived experience depends upon the manner in which it was experienced. In phenomenological research, the concern is not to measure events or their impact on individuals. That is the goal of the positivist movement.

To understand human experience, phenomenologist researchers state clearly that they cannot decontextualise it or analyse it outside its meaning in a particular place and moment: “We are not, and cannot become, the neutral and dispassionate observers that both empiricism and rationalism would have us to be” (Freeman, 1995 citing Packer and Addison, 1989). Far from it, we must recognize that in research, namely in phenomenological research, we are always participants. We read reality, text, speech, gestures, events, stories or whatever, only through our sights, shaped in a particular setting: the individual, familiar, social, historical, political, economic or philosophical context. Heidegger (1984) acknowledged that gender, culture, history and related life experiences influence and contribute to our interpretation of shared meanings.

Many authors claim the need to bracket researcher’s thoughts, ideas or comprehension of the phenomenon. However, in phenomenological interpretative research we are challenged to use these, to reflect upon them and to explore them in order to expand the insight into a particular issue (Gadamer, 1979). It can even be said that the objective world is not so objective, since we describe the world through our experience of the world. This includes feelings and emotions:

If I had no emotions I could not even begin to understand the love poetry of the Elizabethans, but I can only understand it properly by reading about that period. Once I understand the poems I can gain insight into the thoughts and emotions of people very different from me and this extension of my imaginative insight into human nature will, in turn, help me to understand my own muddled feelings better. (Dilthey, 1900 cited by Todres and Wheeler, 2001)

Furthermore, in extending this idea, Gadamer (1979) stated clearly that a researcher’s prior understanding of a phenomenon is not an obstacle but, rather, a precondition of truth. Thus, it is important to make researcher’s prejudice explicit,



that is: “our situatedness in history and time” (Koch, 2006, 1994 citing Thompson, 1990) and “the conditions by which we encounter the world as we experience something” (Koch, 2006, 1994). Hermeneutic reflexivity is an adequate tool in the field of phenomenological research because “it’s a grounded, reflexive and humanized way to explore insight into existential experience” (Todres and Wheeler, 2001).

This grounding is important because “nursing research often approaches phenomena that are complex and subtle and best defined by reference to concrete experiences which give them their substance” (Todres and Wheeler, 2001). It involves reflexivity, as one’s own experiences and one’s attitudes in a particular time and culture “colours the interpretations one makes about sickness, well-being and caring” (Todres and Wheeler, 2001). Furthermore, hermeneutic analysis is humanised because the focus is on phenomena that cannot be reduced to physiological aspects once they are within the subjectivity of human experience.

According to Gadamer (1994), hermeneutics is not a philosophical position but a philosophical task: a hard task of understanding someone through that person’s words at a particular moment in time. It is not an explanation or a conceptualization movement but an uncovering movement of finding the underlying structure of the so called “Dasein”, or what Heidegger (1984) described as “being in the world”.

Thus hermeneutics encourages not objectification but listening to one another. In this context, the other “is not an object for the subject (...) but someone who helps us to travel from language to life. This inner conversation (is) the real foundation of hermeneutics” (Gadamer, 1994).

The aim of hermeneutics is not to measure or categorize the lived experience into concepts. As Dilthey (1976) states, what is experienced from within cannot be categorized into concepts. Nor is it merely a matter of analysing language because the fact that words are absent does not mean that we can conclude that

interpretation is absent (Heidegger, 1984). Moreover, hermeneutics is “a philosophy of understanding and interpretation” (Todres and Wheeler, 2001), encompassing text interpretation as well as self-interpretation (Gadamer, 1979).

### **3.2. Hermeneutic phenomenology in nursing research**

“In nursing, it could be argued that the articulation and description of ‘human experience’ as an ongoing endeavour is fundamental to practice” (Todres and Wheeler, 2001) and hermeneutics is a way to achieve this by mastering an accurate understanding of the world, besides any particular theoretical knowledge. It is an existential understanding: a “largely unexpressed capacity, an art, interwoven in our own lives” (Gadamer, 1994). It is not speech analysis. Interpretation is the pursuit of transparency behind the words, knowing that “every effort of understanding needs to be appropriated, strengthened and secure” (Grondin, 1994). Thus, the hermeneutic quest is to attend constantly to what is tacitly meant, even though not openly expressed, and a way of putting that understanding into words (Grondin, 1994). In order to create an understanding of phenomena, we appeal to the hermeneutic cycle. As this expression makes clear, this is a circular movement: from text to interpretation and from interpretation to text:

- Firstly, we must read the entire text to create a first interpretation.
- Then we analyse each piece of the text to create a new interpretation moving forward from the previous one.
- Once again, we go to the text, and read it again.
- Then the process is repeated again, building a multilayer analysis and interpretation.

Nevertheless, before all these efforts it is necessary to make explicit the researcher’s thoughts and beliefs (Gadamer, 1979).

The use of hermeneutic phenomenology in nursing research is a recent development. Despite the fact that qualitative research arrived in nursing in the late 1960s, phenomenology only appeared in nursing research in the 70s, gaining a cautious acceptance, and not until the late 80s did it start to be more widespread (Todres and Wheeler, 2001 citing Anderson, 1991). A more consistent emergence of hermeneutic inquiry only took place in the 90s (Koch, 1999). The work of Jean Watson and Patricia Benner are perhaps the most well known worldwide (Roth and Tobin, 2001) but many other researchers have developed significant contributions to knowledge, using phenomenological hermeneutic research (Koch, 1998, Corben, 1999, Thornton and White, 1999, Begat and Severinsson, 2001, Roth and Tobin, 2001, Davidson, 2004, Koch and Latimer, 2006, Koch, 2006, 1994).

Also, in the last ten years, there have been several contributions which help clarify methodological issues related to the decision trail in hermeneutics and make explicit the interpretation task (Freeman, 1995, Baker, *et al.*, 1998, Annells, 1999, Clayton and Thorne, 2000, Wimpenny and Gass, 2000, Lowes and Prowse, 2001, Todres and Wheeler, 2001, Kleiman, 2004, Priest, 2004, Whitehead, 2004, Annells, 2006, Koch, 2006, Witt and Ploeg, 2006, Bradbury-Jones, 2007).

Among all the above, the work of Tina Koch (1994; 1996; 1998; 1999; 2004; 2006), merits special attention. Since her first paper in 1994, her studies have been widely cited vis-à-vis rigour in hermeneutic research (Koch, 2006, 1994). Like other nurse researchers (Annells, 1999, Annells, 2006), Koch has clarified that rigour in qualitative research does not oblige different researchers to draw the same interpretations. It is also possible that the same researcher may arrive at different interpretations at different reading moments. However, the hermeneutic product must be clear to allow the reader to understand how the researcher conducted the research and how interpretations arose.

For Guba and Lincoln (1989), rigour relies on credibility, transferability, dependability and confirmability. A way to establish credibility is to return to participants with interpretations. By doing so, it is possible to compare researchers' ideas with the participants' interpretation of the phenomenon. Researchers can ask people what they think about the researchers' conclusions. In the present research, working over a six month period in a biographic seminar for nursing students, I had the opportunity not only to share my interpretations but also to work with nurses to build the interpretation with them. Concerning patients' points of view, interviews were used as opportunities to clarify interpretations.

Another possibility to increase credibility is to develop self-awareness by explicating our thoughts of the issue being studied (Annells, 1999, Annells, 2006, Koch, 2006, 1994). To accomplish this I started exploring my own life history related to autonomy and empowerment. This helped me to identify my life events, beliefs, and attitudes towards my own autonomy and empowerment and towards older people.

Transferability might be considered as the extent to which the conclusions may have sense in another context (Koch, 2006, 1994). To achieve transferability it is necessary to describe adequately the research context (Guba and Lincoln, 1989) in order to allow readers to make similar judgements in similar or different contexts. This is only possible *a posteriori* with the publication and discussion of research results.

Dependability is verified when the study allows another researcher to follow the decision trail and reach similar (or not contradictory) conclusions (Guba and Lincoln, 1989, Koch, 1999). Therefore the interpreter describes the process providing evidence of her or his inquiry. This description allows that each step of the interpretation process can be confirmed (confirmability) (Guba and Lincoln, 1989, Koch, 2006, 1994).

To Freeman (1995), hermeneutics is a circular movement between interpreter and what she or he already knows and the text. In each round, the interpreter revises and corrects her or his understanding “as a function of what the text itself says” (Freeman, 1995). And this is the real challenge in nursing care: to understand the vivid experiences of health and illness and to uncover our prejudices and build meaningful nursing care with our partners (the patients and their families).

### **3.3. Life histories as a research tool**

I chose to use life histories as a data collecting strategy in two different ways. With participant nurses a Biographic Approach Seminar was designed in order to create reflection on practice inside an academic context. Therefore, this experience fulfils both educational and research purposes: nurses would learn from the histories they produced and data generated would be analyzed in the context of the present research. With patients the aim was just to collect biographic material through interviews. Thus, it is important to contextualize life histories and their use in research and education.

Life histories are something as old as human history as we are here talking about story telling: through listening and telling stories about daily life, people’s culture and history is transmitted and identity and memory are built. Besides a literary interest each story encompasses an underlying meaning: whenever we tell a story, messages are passed on beyond the story itself (Cabete, 2008). This is one of the foundations of the use of narrative inquiry in social sciences as a tool to search for knowledge.

The use of life histories as a research tool emerged in the field of social sciences after the First World War when the Chicago School started to use people’s stories as an open window to understand individuals in their situation at a particular time and in a particular context (Fontes, 2008).

Thus, life histories came out as a tool to find particularities inside groups of individuals that shared a common characteristic (e.g. immigrants); through understanding of social representations or beliefs of an individual we may understand social representations of that person's group (Fontes, 2008). Consequently, the interest is not the single person but the similarities inside a group of individuals who share a common characteristic. It is interesting to note that the Chicago School focused on the understanding of deviant behaviours in urban environments strongly influenced by social stigmas in a chaotic city full of socially excluded groups (Tinoco, 2007).

However, in spite of its rise at the beginning of the twentieth century, in the 1920s and 30s, the movement of life histories was minimised by the emerging positivist movement with its quantitative methodologies. Later on, at the end of 1960s, life histories re-emerged as a research tool in the hands of sociologists and anthropologists, who argued that an individual's life encompasses a meaning bigger than that life in itself (Fontes, 2008).

From sociology and anthropology, life histories then gained their place in social sciences, particularly in psychology. Nevertheless, despite the affirmation of the life history, the discussion about trustworthiness and validity remains as it may be alleged that those who tell a story are telling their version of the story: either the one they want to tell or the one they assume the researcher wants to hear. It is also arguable that participants may either use their imagination in creating stories, or keep information, or even be limited to the memories they are able to recall at a particular moment (Dyson, 2005). However, "a basic premise of the hermeneutic phenomenological method is that a driving force of human conscientiousness is to make sense of experience" (Cohen, Kahn and Steeves, 2000, p. 3) and through story telling each person is conveying the sense of her or his own experience (Dominicé *et al.*, 1998). Hence, the issue is the rigour and accuracy of the process and not the quest for a quantitative validity.

There is widespread discussion about whether the biographic approach is a methodology or simply a data collecting strategy (Gauthier, 2005); however, in this research, it was used as a sensitive way of gathering data with two different groups of participants: with patients, through interviews to obtain biographic data related to autonomy and empowerment, and with nurses, in a more complex way, as a seminar with the double purpose of promoting a learning experience and gathering data for this research project.

Moreover, if the use of life histories in nursing research has a short history, its use in the educational context is even shorter, as the first experiences reported date from the 1980s. According to Pineau (2006), in the development of the use of life histories in education, three stages may be identified: the outbreak (during the 1980s), the grounding (during the 1990s), and the differentiation (during the present decade). During the outbreak period, the work of Gaston Pineau (Pineau, 1983) is referenced as he states that it is possible to find a learning dimension in the search for meaning in each individual's story; namely, in adult education. This means that the analysis of lived experience by the subject who lived it may support a learning process: a quest for meaning is a quest for knowledge.

Regarding the field of adult education, in the 1980s it is also important to cite the work of Nóvoa and Finger (1988), who contributed to expanding knowledge. From then onwards, the use of life histories increased in the educational field in order to explore learning processes, to build projects or to acknowledge learning acquisitions (Pineau, 2006). During the next decade, the method starts to be used in diverse professional environments. The *Association Internationale des Histoires de Vie en Formation* appeared and publication and discussion of the method increased. Only in the present decade, however, has Life Histories in Education emerged as a topic in graduate or post-graduate education and its increasing use has raised the need to clarify some concepts used. Moreover, different approaches of this method have been developed (Pineau, 2006):

- Biographic method: the narrative of someone else's life; the professional (researcher or tutor) collects the data to build individuals' life histories;
- Self-biographic method: the narrative of someone's own life; each person writes her or his own history and the researcher or the teacher just reads, listens or facilitates the process;
- Dialogic or interactive method: a combined work where the quest for meaning is not limited to actors' awareness or researchers' analysis.

Another issue in differentiation relates to the comprehensiveness of the biographic work. In other words, it is possible to work on a full life history, where the aim is to obtain a complete biography of someone, or just to produce a biography focused on a pre-determined issue (Tinoco, 2007). Furthermore, it is also important to clarify that the work on life histories for educational purposes may be done individually, where each individual tracks alone the pursuit for meaning in his own history, or in a collective way, when the quest for meaning is discussed in small groups and the analysis and interpretation of each individual history may receive contributions from others which are also involved in biographic work (Josso, 1991, Dominicé *et al.*, 1998, Josso, 1999, 2002). In whichever case, the quest for the meaning of the lived experience and its learning outcomes is the core interest of life histories in education (Pineau, 1983, Dominicé *et al.*, 1998, Pineau, 2006).

Owing to my own education and personal experience, for the purpose of this research, the dialogic method was chosen (where researcher and participants interact), focused on a specific issue (autonomy and empowerment), in a group approach with nurses. The biographic approach with patients followed a different path: with nurses, the aim was to include a learning process, in addition to data collection. With patients, there was no explicit educational aim. Moreover, even if the process will be explained later on, it is essential to explore the rationale of the elected method, mainly grounded on Josso's experience (1991, 1999, 2002, 2006).



According to this author, the challenge is to answer a simple question: I know the experience I had: and now what is its use? What shall I do with my lived events? And by answering to her or his own questions, a renewed insight of the learners on their own formative experiences arises (Josso, 2002). By “formative experiences” is meant narrative testimonies of significant memories, considering “significant” those which brought something new, some refreshed knowledge. In other words, it is a conscious effort to identify events through the lifespan that lead to new skills, new attitudes or new knowledge. Hence, work on formative experiences is to tell oneself one’s history, searching for meaning in the lived events. It is to travel towards the inner self through a reflexive process of articulation between the “lived” and the “learned” that might lead to life wisdom (Josso, 1991).

And this differentiation between the “lived” and the “learned”, between “the event” and “the experience of the event” is one of the cornerstones of the biographic challenge. In the field of life histories in education, the experience being the result of the reflection, of the cognitive elaboration of the lived event, it is possible to live many events, or to live the same event many times, without building the experience (Josso, 2002). This means that we may blow out the candles of a cake many times without thinking about the reasons we do so, about the emotions involved, or about how strong the air blow must be. If we live the event (like blowing out candles on a cake) but do not think about it, there is no experience in it. Hence, experience is related to new knowledge and a rediscovered meaning. To this extent, experience is not a quantitative concept as it does not matter how many times I did something, or something happened to me, but it does matter how deeply I thought about it.

Thus, the work of life histories may be defined as the movement through which an individual transforms lived events into experience. And the key point is the selection of these events: the “significant” events. Furthermore, it is vital to make explicit that “significant” is not related to “emotionally intense” or “cognitively

demanding”, as the extent of “significant” is defined by the individuals concerned (Cabete, 2008). Each person involved will elicit the events they consider to be significant: those which meet the criteria of “formative”.

Nevertheless, taking into account that from some events one may learn just little things but from others it is possible to learn substantial lessons, Josso (2002) makes a distinction between “formative experience” and “foundational experience”. In the first case, any situation that teaches something to someone is a formative experience. One might have many experiences over the lifespan, as it is possible to be continuously aware of our actions in order to work them out cognitively: it is the appropriation of an individual’s life at a cognitive level. On the other hand, “foundational experiences” are those which dramatically change our mindset, which interfere with the way we see the world, which change our behaviour, both in a professional context and in the broader context of life: thus, we have only a few in a lifetime.

Experience is also a decision: as stated before, it is possible to blow out the candles without any added knowledge but it is also possible to reflect on it. And this critical thinking over a phenomenon may be *a posteriori*, i.e. at a particular moment in time, someone decides to analyse previously lived events that become experience some time after, or one may decide to have experiences *a priori*, i.e. to deliberately choose to live (and to plan) some event (Josso, 2002). In this latter case, the subject goes to the experience with a learning intentionality. Thus, the author talks about “having the experiences that life brought me”, “doing experiences that I decide to do” and “thinking about those experiences”, to differentiate experiences *a priori* or *a posteriori* vis-à-vis the moment when the decision took place: prior or after the lived event. And this also distinguishes occasional (or accidental) learning from an organized process of building or discovering the meaning of the events in one’s education, professional practice or in life.

Thus, the challenge of using life histories in education is to expand the consciousness field, to identify focal points of learning, discovering their underlying meaning. Moreover, it is to develop an intellectual openness to new knowledge, to whatever significant events might happen in the pursuit of life wisdom (Josso, 2006). Therefore the “apprentice” will learn to be a self-spectator, to be a stranger to herself or himself, to be astonished at previously familiar things. Hence, blowing out the candle will no longer be an automatic gesture, this will be replaced by a self-awareness of things, of events, of gestures, by a constant questioning and by a real life-long learning experience determined and owned by the long-life learner. Therefore, the past may change, not because the story changes (the event is the same) but because the way we see it changes. Consequently, future actions will be different and, in this extent, it might be said that it is necessary to change the past to change the future (Cabete, 2008).

The experience *a priori* comes through a conscious decision regarding an expected outcome. The research is an *a priori* experience as the trail is previously designed in order to obtain new (or renewed) knowledge to answer questions formerly designed. In life histories, the apprentice asks herself or himself questions such as “What meaning do I give to my history? What events did influence me and my practice?” and, through the attempt to answer these questions will find links between an action and its rationale (Josso, 2002).

Thus, moving from lived event to learning experience is also a research movement (perhaps a self-directed one) looking to understand individuals in their context (their lives), trying to uncover behaviours and the reasons behind those behaviours. Furthermore, it is also an empowering methodology because it is self-directed learning and self-directed research: each one will choose experiences she or he wants; data are generated by participants; each individual will reflect on his or her practice; learning is in the hands of each individual. And even if sometimes the focus is on learning outcomes, while on other occasions the focus may be on

research, to the extent that the aim is to identify significant experiences, it will always be simultaneously research and learning (Josso, 2002)

However, some steps are always present, either for research or just for educational purposes, as the biographic work encompasses three different phases (Dominicé *et al.*, 1998, Josso, 2002, Cabete, 2005a, Josso, 2006, Cabete, 2007, 2008):

**A. The preparatory phase:**

The process starts with discussion about the rationale of the use of life histories: how the methodology arose, what its underlying principles are, what the tasks are to perform, what the expected outcomes are, and what the ethical implications are. The aim is to clarify the purpose and the trail in order to allow a full and constructive participation.

**B. The narrative phase:**

The second stage is the production of narratives, either individually or in groups, either oral or written narratives, either an entire biography or one related to an issue. According to Josso's framework (as well as my own experience) the process consists of creating narratives related to a specific topic (in this study autonomy and empowerment); the first step is an oral narrative (more spontaneous) and then a written one (more analytic). This work is accomplished in small groups (3 to 4 nurses).

**C. The analytic and interpretative phase:**

The third stage consists of converting event inventories into an appropriation of knowledge through an interpretative trail linking past, present and future, connecting action to knowledge. The work is done by single individuals, in small groups (3 to 4 persons) and in a larger group.

### **3.4. Participants' sample**

In the field of qualitative research, selecting participants focuses on having significant sources of data, rather than on having huge samples or on applying probabilistic methods (Streubert and Carpenter, 2002). The relevance of data comes from its significance and by the way each source of information is approached and explored. Hence an intentional sample (also called non-probabilistic) is an appropriate procedure, as the researcher chooses a place or a group of individuals that she or he considers adequate to the research purpose (Fortin, 1999, Marshall and Rossman, 1999, Streubert and Carpenter, 2002). For many authors, the handicap of intentional samples is that it is impossible to know if participants are representative of the population; however, in phenomenological research, the interest is not in generalizations but in understanding the phenomenon at a particular moment in time as it is experienced by a particular group of people (Cohen, Kahn and Steeves, 2000).

Finding the adequate sample may be a difficult trail, involving several sampling decisions in order to define how many participants are necessary and what the perfect system to select them is. However, as Marshall and Rossman (1999) state, it is better to conduct research using the sample possible, than not to undertake it because the perfect sample is unreachable. Hence, the soundness of the sample in qualitative research is related to the description of sampling decisions (Marshall and Rossman, 1999, Cohen, Kahn and Steeves, 2000). Consequently, within the multiple choices available, the intentional sampling process to select the participants was chosen, owed to being appropriate to phenomenological research (Marshall and Rossman, 1999, Cohen, Kahn and Steeves, 2000). In an intentional sample, the researcher chooses participants according to her or his knowledge of their experience related to the phenomenon (Marshall and Rossman, 1999). Furthermore, in an intentional sample, participants are present in a particular setting, at a particular moment in time, accessible to the researcher (Fortin, 1999).

This type of sample saves time, money and effort, even though some authors argue this could limit the information collected (Marshall and Rossman, 1999). However, this was the sample possible as I am a part-time student with a full-time job and, thus, the accessibility to participants was an important criterion.

Besides the type of sample selected, it is also necessary to define its size. According to some authors, sampling does not end until data saturation has been reached (Streubert and Carpenter, 2002). However, the concept of data saturation is also questionable, as it is difficult to be sure that no new information will be acquired. Moreover, as Gauthier (2005) states, Newton only had to look at the apple once to discover gravity. Nevertheless, this is an issue that the researcher has to keep in mind: to be attentive in order to identify when to stop recruiting participants.

Hence, the participants in this study were nurses caring for older people in acute hospital settings and hospitalized patients aged 65 years or older. It is also important to state that the nursing and patient samples are not related. The selection of participants is described subsequently, as well as the sampling decisions made.

### **3.4.1. Participant nurses**

Nurses were recruited during a 1-year academic taught programme that takes place in Portuguese nursing education<sup>5</sup> in the institution where I was a lecturer. Since 2002, forty vacancies have been offered every year and a selection process takes place as more than a hundred people apply.

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<sup>5</sup> Portuguese nursing education background is explained in Introduction, under *Research Context*.

This particular academic year is based on adult education philosophy, as staff attempt to use it as an opportunity for students to reflect on and change nursing care practice through project-based learning (Cabete, 2005a). From the beginning, and following my proposal, critical analysis of practice was undertaken using the biographical methodology (Gillick, Serrell and Gillick, 1982, Dominicé *et al.*, 1998, Josso, 1999, 2002, 2006), around the trilogy: health, illness and nursing care.

Throughout the semester, teachers and students discuss, question, highlight and analyse concepts, theories and nursing models, simply starting by exploring lived experiences (not only as professionals but also as persons that give and receive nursing care). The biographical methodology has been an excellent experience, with recognized profits in practice for teachers and nurses (Cabete, 2005a). I have been involved in it from the beginning and wanted to go a little further and use it also as a research tool. Thus I proposed that for the academic year 2005/6 the issues for discussion in the Biographic Approach Seminar would be “Autonomy, Empowerment and Nursing Care”. This proposal was accepted by the necessary school committees (Cabete, 2005a) and a detailed plan was produced.

The Biographic Approach Seminar involves 2 teachers, both having the same post-graduate diploma in “Life Histories in Adult Education, in Research and in Clinical Practice”. Each teacher leads one group of students. As my colleague had professional experience in the paediatric and young adult population and being myself a clinical specialist in geriatric care, the students are enrolled in each teacher’s list, according to their own professional experiences. This criterion is explained to the students. Hence, both groups have the same opportunity to reflect about practice and to produce life histories. The only difference between the two groups is that the nurses of my group were invited to participate in the study.

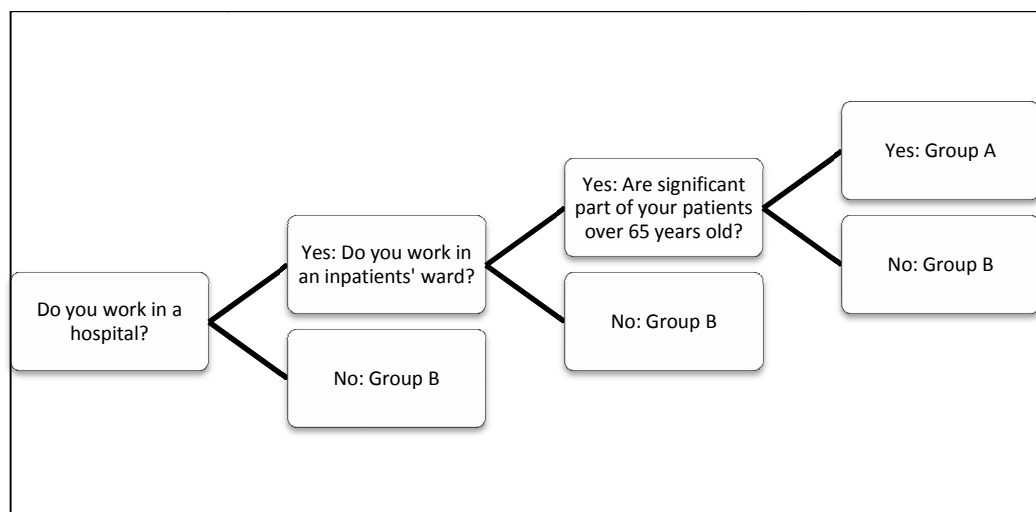
It is also important to state clearly that, despite being part of a course, the Biographic Approach Seminar has always been outside any quantitative or

qualitative assessment, and all the experiences shared by participants are confidential. An ethical commitment is discussed and signed by all participants (teacher included).

The aim is to reflect on daily nursing practices, to challenge nurses to question their nursing concepts and beliefs, developing critical thinking skills in a secure non-judgemental environment. The accreditation of the seminar, in the students' curriculum, was just by attending 75% of the previewed meetings. The previous experience evidenced an enthusiastic adherence from students (with an overall session attendance rate of 98%) and engaged participation.

This year, 41 students were enrolled in the course. Three questions were posed to all students in order to obtain 2 groups: one group of nurses that work in hospital settings and have daily contact with hospitalized older people (Group A – probable participants) and a second group of nurses working with a predominantly younger population in or out of hospital settings (Group B). The flowchart of selection criteria is in Figure 6.

Figure 6 - Nurses' inclusion criteria



Group A was composed of 20 nurses, all female, having from 5 to 31 years of professional experience in hospital care. All nurses declared to work in acute



hospital units caring for a population ages 65 years old or over. As there was no intention to explore socio-demographic variables, no further characterization data was collected, as it is not ethical to collect data if it is not to be used (Fortin, 1999). In the first meeting with the group, the research aim was discussed and it was explained what the participation would be: after finishing the semester, those who would like to participate should return individual material (audio records of oral recitals, written narratives and learning diary) and have an interview. It was also made clear that each one could return the material they wanted to (there were no conditions regarding the extent or quantity of material to be returned).

Table 1 – Summary of nurses' participation

Nurse	Oral recital	Diary- notes	Written recital	Interview
N1	Yes	Yes	Yes	Yes
N2	Yes	Yes	Yes	Yes
N3	Yes	No	Yes	Yes
N4	No	Yes	Yes	Yes
N5	No	Yes	Yes	Yes
N6	Yes	Yes	Yes	Yes
N7	Yes	Yes	Yes	Yes
N8	Yes	No	Yes	Yes
N9	Yes	Yes	Yes	Yes
N10	Yes	Yes	Yes	No
N11	Yes	Yes	Yes	Yes
N12	No	No	Yes	Yes
N13	Yes	No	Yes	No
N14	No	No	Yes	No
N15	No	No	Yes	No
N16	No	Yes	Yes	No
N17	No	No	Yes	No
N18	No	No	Yes	No
N19	No	Yes	Yes	No
N20	No	No	Yes	No
Sum.	10	11	20	11

The material should be dropped in my mail box, after the end of the seminar, together with a signed consent form and contact details in order to book the interview. All 20 nurses were invited to participate in the study and all accepted. I received 20 written narratives, 10 oral recital audio tapes, 11 learning diaries and 14 signed informed consents forms for interview but only 11 interviews were actually obtained as 3 nurses did not keep the interview appointment. A summary of nurses' participation in data collection is shown in Table 1.

### ***3.4.2. Older Patients***

The older people participating were individuals aged over 64, selected by intentional sample from one general hospital in Setúbal District. As there are no geriatric wards in Portugal, a general hospital was selected. Since the medical departments have the most significant prevalence of older people, I asked for permission to select participants there. This option was also related to the need to exclude patients subject to surgical related interventions such as anaesthesia and analgesia, which might influence cognitive status. One ward was selected by the Administration Board, according to Ethical Committee recommendations: a ward with 15 patients in the Cardiology Department.

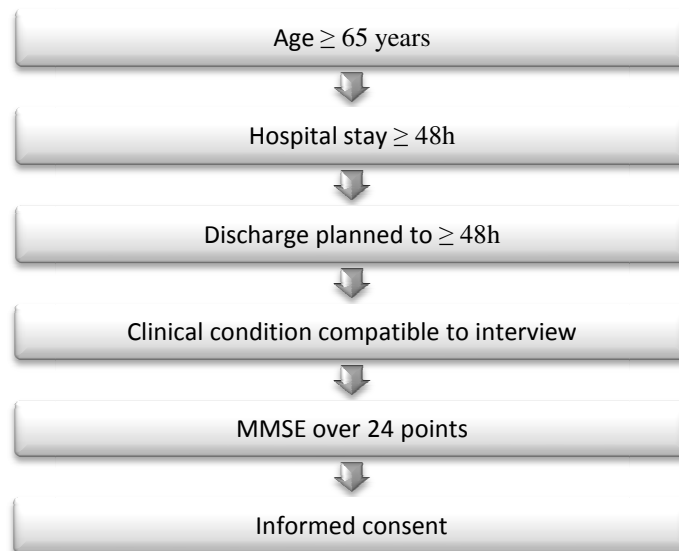
After obtaining the necessary authorizations I commenced the data collecting process, which occurred from the 26<sup>th</sup> September 2006 up to the 14<sup>th</sup> January 2007. To select participants, I met the head nurse, in order to apply the first four inclusion criteria:

- Selected range of age (patients aged 65 years old or over);
- Having at least 2 days of hospital stay, to ensure a clinically stable condition;
- Having discharge planned not before 48 hours, to allow a second or a third interview during hospital stay;

- Allowing interview without implications for clinical condition. In other words, according to primary nurse assessment, to talk up to one hour would not cause any predictable harm.

After passing these criteria, the patients identified were approached in order to assess cognitive condition using the MMSE – Mini Mental State Examination (Folstein, Folstein and McHugh, 1975) as this is a very popular test in many hospital settings in Portugal. This test scores up to 30 points. The cut-off point of 24 was used – below this point, dementia might be present (Gallo et al, 2000, p. 54). The aim of performing a cognitive assessment was related to the need to ensure both that a coherent and meaningful discourse was possible (to allow research) and that patients were sufficiently aware to understand and undersign the informed consent form, thus complying with ethical standards. Subsequently, informed consent was sought. All the patients fitting these criteria at the time of the start of data collecting were invited to participate. Refusal was respected. The process was repeated by applying sequentially the criteria as presented in Figure 7.

Figure 7 - Patient's selection process



As it is essential in phenomenological research to vary testimonies in order to catch the essence of the phenomena (Streuber & Carpenter 1999), I wish to select patients with gender and age diversification. Thus, the sample should cover both genders and two different ranges of ages: from 65 to 74 years old and 75 years old and over. Hence, the need to collect information from different groups of people is not related to the need to undertake any statistical stratification, or any correlation to demographic characteristics of older people, either in society or inside hospital, but simply to the attempt to widen the analysis of the phenomenon as much as possible.

The need to vary the range of age is related to possible differences pointed out by some authors: a decrease in autonomy after 70, 75 or 80 years of age (Berger & Mailloux-Poirier 1995, Cabete 2001, Gallo et al 2000, Lichtenberg et al 2000, Sager et al 1996, Wu et al 2000). However no stratification sampling took place, as the aim was to vary testimonies and not have representative percentages of any population.

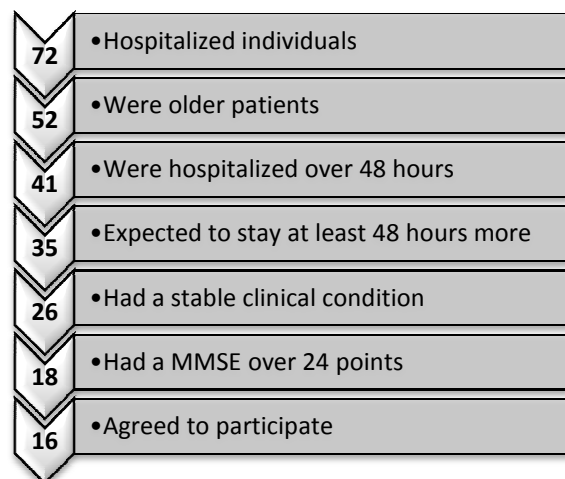
Table 2 – Check-list of patients' inclusion criteria

Check-list of inclusion criteria - Round 1								Participants			
Bed Number	Empty bed	<65 years	<48h of hospital stay	Discharge planned in less than 48h	Interview not recommended by primary nurse	MMS <24	Informed consent	Gender		Rank of age	
								Male	Female	65-74	≥75
1		X									
2					x						
3		X									
4		X									
5				X							
6						25	Yes		X		80
7						25	Yes	X			80
8						29	No				
9	X										
10		X									
11			X								
12						28	Yes		X		75
13						28	Yes		X	67	
14	X										
15					x						

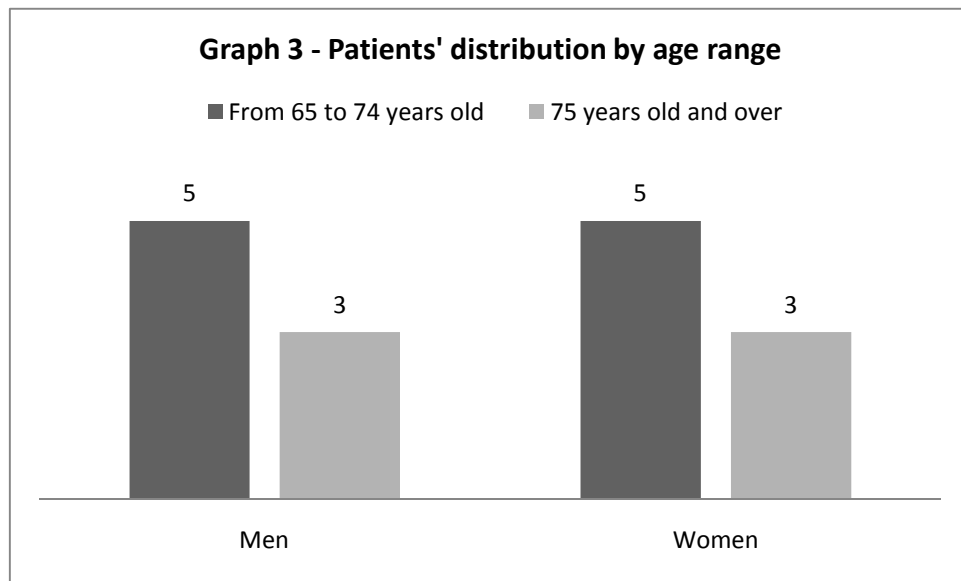
Thus, the sampling process went on until the different genders and ranges of ages had been covered, as I wanted to balance the sample for age and gender without having to refuse some patients on the basis of their age or gender. In order to keep a rigorous record of the process a check-list with these criteria was compiled and applied, as exemplified in Table 2.

I picked up all selected participants and followed them up to the discharge day. Once the last patient of each round was discharged I started the process again. Six rounds were performed, when data saturation seemed to occur and participants represented the range of identified variables. The tables of the 6 rounds are in Appendix 1. In Figure 8, the overall process is systematized.

Figure 8 - Patients' sampling process



Hence, sixteen participants were included, six male and ten female, from 67 to 90 years old. Graph 3 shows a distribution of patients by gender and age range that met the expectations of varying testimonies.



As the purpose of this research is not to explore socio-demographic variables, no further data was collected about patients, for ethical reasons. Nevertheless, reading the narratives it is possible to find some more information. Regarding participant's background, they were all born in Portugal between 1916 and 1939 and lived their entire lives in the southern part of the country. More than half of participants' live was lived during dictatorial times, as the outbreak of democracy was in 1974. According to patients' narratives it is possible to say that at least two of the men fought clandestinely the fascist regime and one was a political prisoner before the revolution. As far as family situation is concerned, all men were still married and lived with their wives. Conversely, women had diverse situations: four women were widows (one lived alone, one lived with a brother, and two lived with their children) and four were still married, living with their husbands. All participants live in an urban environment and are retired, even though six of the women never had a job.

As this research involved persons who shared life events, feelings and emotions, it was absolutely essential to respect privacy, anonymity, confidentiality of data and the right to refuse or drop out of research. All participants were volunteers and

gave written informed consent, receiving all information they needed in order to accept, refuse or drop out at any moment, without any consequence or benefit.

Patients were given information sheets to read and sign. Large print versions were available to patients having sight difficulties. As in Portugal almost 30% of older people are illiterate, the head nurse or the primary nurse was asked to witness the informed consent process. This is a common practice in Portugal and has been used before in previous research (Cabete, 2002).

### **3.5. Data collecting strategy**

The data collection process followed different ways with nurses and with patients, both in structure and in time. Nurses participated in a Biographic Approach Seminar over a semester, whilst patients were interviewed in hospital, with a few days' interval between each interview. The processes were different and not contemporaneous as it would not have been possible to achieve this: biographic work is a demanding task, both at a cognitive and an emotional level, and has to fit in with the course programme, while patients could be discharged at any time. Moreover, patients and nurses were not connected.

#### ***3.5.1. Structure of biographic work with nurses***

The Biographic Approach Seminar (BAS) was structured according to the theory and methodology of Life Histories and Biographic Approach for Research and Education (Josso, 2006, Josso, 2002, Josso, 1991, Dominicé et al., 1998, Josso, 1999) and consisted of 9 group interactive sessions, each one taking nearly 3 hours. As biographic work is an interactive methodology, nurses were invited not only to produce narratives but also to discuss their findings. Starting with individual experiences, each one was challenged to analyse his/her understanding of nursing practice in relation to autonomy and empowerment. Through this

process, participants are encouraged to write a diary including thoughts, feelings, founding, and questions.

The sessions were, for the most part, in a large group (20 students and the teacher) but 2 sessions were in small groups (of 4 students) and the teacher was available for support, if required. Some work was also done individually by students, particularly the written task. Below, each session is briefly described, and its aims and activities presented.

A room of adequate size was chosen, appropriate for 21 people, and chairs disposed in a circle to make the environment more comfortable and without barriers between teacher and students.

I developed and accomplished the biographic seminar with 20 volunteer nurses, and a detailed plan was drawn up in order to be used as a guide through the sessions. The BAS ran in the first semester of the Complementary Year. Each academic semester has 18 weeks (in Portugal) and sessions had a weekly basis, held on Friday afternoons. Whenever students were asked to prepare some work, some gaps were scheduled (1 week to prepare oral recital, 3 weeks to do the written narrative and 3 weeks to analyse colleagues' narratives). The BAS ended two weeks before the end of the semester.

### **Session planning**

The first session took place in the large group, its aim being to break the ice and to present structure, underlying concepts and methodology of BAS. The issue of life histories was then discussed and its use contextualized in research, education and clinical practice. A written text containing the underlying concepts of biographic work was given to students. The main concepts were discussed; namely, the concepts of formative events, significant events, learning experience and foundational experience, as described before. The aim of the seminar was also discussed and the students were encouraged to start a learning diary, beginning by



writing their first thoughts about the methodology and its challenge. The diary form, support, extent is free and may be creative.

The second session started with a discussion about the fundamental concepts of biographic work. Then issues of autonomy and empowerment were introduced. Students were asked to give synonyms of these words and an informal discussion was encouraged. The aim was also to explore spontaneous concepts and to continue “breaking the ice”, encouraging free and spontaneous participation. Special attention was given to the inclusion of all students in the discussion. From nurses’ participation, it was noticeable that the concept of empowerment (and even the word in itself) was unknown for the huge majority; a few theoretical topics about empowerment were thus introduced in order to focus the group. This unawareness was quite a surprise to me even if I knew the word empowerment does not exist in the Portuguese language (or in any Latin language). We do have several approximate synonyms but any one (alone) does not have exactly the same significance. However, the English term is used in academic and professional environments. Hence, it was important to clarify the basic meaning of the word, as it would not be possible to share experiences related to a topic that most of the nurses did not know.

The third session intended to prepare the oral narrative by discussing its aim, structure and clarifying its rules. To start, each nurse would be asked to share significant events (considering as significant those that each author considered as a situation that brought something new: new knowledge, new behaviour, new feelings, as explained before); however, in this, there is no obligation to share events that might violate participants’ intimacy, as the aim is not to share “secrets” but to share formative events. The recital is spontaneous and no particular order is needed. Even though this is not group therapy, sometimes some emotional catharsis may happen. It must be faced and accepted as a natural part of life, as life and learning involves emotions. Psychological support was available, if anyone should need it. Nevertheless, it is important to keep in mind that the

focus is on learning outcomes. Another important point was that each nurse should talk from 30 to 45 minutes without any kind of interruption from colleagues. Silences should be respected, even if long silences occurred. No one was allowed to ask questions, or make judgements. After finishing the oral recitals of the small group, students could share their feelings about the listening endeavour, but the content of each narrative is to be thought about and not to produce immediate discussion.

After clarifying the rules, ethical implications were discussed and an ethical commitment was undersigned by all participants (teacher included). Once more, the aim of BAS was remembered. The students were encouraged to visualise a trunk, as a metaphor for confidentiality. “Imagine we are the components of a trunk: to keep its contents, the trunk needs all the parts to do its job. It is not enough that the trunk has a good lock. It needs all its metal and wood pieces in their proper places.” It is vital to remember that we are having access to confidential information from each other and it must be treated as classified data. The session ended with the oral narrative of the teacher, the only narrative offered in the large group. Two aims were considered: to demystify something unknown; to eliminate (as far as possible) some fears, providing a practical example as it is easier to understand what a life narrative is after listening to one. Students were encouraged to write in diaries what they had learned by listening to the teacher’s narrative.

Between the third and forth sessions, there was a one-week break. Participants were asked to write topics to facilitate oral narrative according to the teacher’s instructions. The aim was not to write about the events, but to give the titles of the events they would like to share. As most of the tasks related to BAS, this was not compulsory but could make the oral recital easier. In addition, students formed small groups, following their own preferences. The recommendation was to look for differences and not for homogeneities, i.e. the work would be richer if younger

nurses were mixed with older nurses and if people that did not know each other joined together. Again it was not compulsory, but just a recommendation.

The aim of the fourth session was to produce oral narratives in small groups (3 or 4 students), in special rooms booked for this purpose. As the rooms are soundproof, they are good for privacy and suitable for recording audio recitals. The audio record was not to be shared and it was kept by the owner. After finishing the BAS, this record could be dropped into the teacher's mail box for research purposes or deleted or even kept by the owner.

During the fifth session, reflexive thinking over autonomy and empowerment was begun. Each one was asked to share what they learnt, discovered or revealed about autonomy and empowerment by listening to themselves and others. The focus was "what did we feel and what did we learn?" Then instructions to make a written narrative were given clarifying that the style, presentation and extent were absolutely free. The narrative could assume literary creativity and should follow a line explicated by the teacher, such as a time line or a thematic line, for example, and some analysis should be present: thus, in addition to the event story, students should report learning outcomes, changes, questions. Each student should bring 4 copies for the following group meeting: one for each member of the small group and one for the teacher (it was clear that this was for learning purposes, independently of research purpose).

Between the fifth and sixth sessions, there was a three-week break to allow the necessary time for the writing task. Participants wrote down an organized narrative, using the audio record as starting point (if they wished). The aim is not to do a simple transcription of the oral narrative (which is much more spontaneous) but to organize the narrative by selecting significant events around the questions emerging during this process (what came out from my memories?), describing events (what happened in those events?), analysing why are they

significant (how did I feel?), analysing its formative impact (what did I learn?) and exploring its meaning. Thus the focus was to follow the reasoning.

The aim of the sixth session was to continue reflexive thinking over autonomy and the concept of empowerment through the writing experience by analysing what each one had learnt, discovered or revealed about autonomy and empowerment, by listening to one's own narrative, and by reflecting upon its similarities and differences, vis-à-vis different narratives from different colleagues. Subsequently written narratives were exchanged in the small groups. Some recommendations were given for the analytic and interpretative reading task.

Between the sixth and seventh sessions, a three-week break took place to allow participants to read colleagues' narratives (from the small group). This reading was a quest for meaning. Written narratives were analysed and interpreted and questions to discuss around the topics and concepts should be written in order to further discussion in the small groups.

The aim of the seventh session was to work in small groups in order to thoroughly understand students' analysis by discussing upon the written narratives. Hence, each student gave feedback to colleagues about her or his analysis and interpretation of each narrative. Discussion and validation of these interpretations were the core issues of the session, moving towards a conceptual discussion of autonomy and the concept of empowerment emerging from the differences between each of the narratives. The key question was "I think that through this event autonomy means to you... Am I right, is it a possible interpretation?" Again, the teacher was available but not present in the groups.

In the eighth session, the task was to transfer discussion, finding and reflections to a wider context. Findings, questionings, reflections, and concepts were discussed and students were encouraged to transfer the knowledge from the small group to the context of nursing care and of professional evolution and practice. In the large

group, conceptual maps of empowerment and of autonomy were built up through interpretation and analysis of each group. Some work on linking group findings to theoretical knowledge was undertaken. Students were encouraged to write about this in the learning diary.

In the ninth session, the large group met for the last time to discuss the process and the findings, the constraints and the learning outcomes. A synthesis was made by the teacher and each participant was invited to talk about vivid experiences in the BAS. A closing ritual was enacted: the last minutes were used to say goodbye and to point to future uses of the learning outcomes. I took twenty-one pieces of string (each three feet long) and gave a piece to each person (teacher included). Imagining that each piece of string represented the pieces of shared individual stories, I asked everyone to stay in a circle and tie the string to the pieces of the colleagues on the left and on the right. The circle was thus closed, symbolizing the “closed truck”, the place inside which we shared pieces of our stories. Then, with scissors, I started to cut my string between the linking points, and the scissors were passed from hand to hand to cut twenty-one pieces symbolizing the goodbye. Thus, each participant remained with a different piece of string in her hands: a piece of string with a knot, part of her string and part of someone else’s string. These two pieces linked by a knot represent, on the one hand, that knots have been tied between participants and those ties may last (if desired) but, on the other hand, they are a reminder of the remaining commitment to ethical issues assumed by all participants. This moment is crucial to reinforce trustworthiness and to close the seminar. From this moment, each one could do whatever she wanted with the experience: to keep it as it is, as a memory in a box, to throw it away, or to expand it. This is each person’s individual decision.

During the whole process, participants were encouraged to write a diary including thoughts, feelings, findings, and questions. To share the diary was completely optional. I was available in my office, every day after the sessions, however long it took, to receive the students if they should need or want to talk to me about the

experience, the constraints, the emotions or anything whatsoever. This was a privileged moment of interaction and even though I did not take notes there were particular formative moments for me as a teacher.

Obviously, the double role of teacher and researcher demanded extra care and frequent clarification regarding students' participation in the seminar and in the research. Hence, from the very first session it was underlined that the BAS was a place of freedom of speech and of dialogue and that all shared thoughts were welcome and respected equally. Moreover, the seminar was always outside any kind of assessment for academic purposes. Each participant was asked to contribute positively to the learning experience, knowing that the seminar would be as rich as the students' participation. It was also clarified that we were not looking for book citations but for nurses' shared experience and critical thinking. Hence we should be worthy to our colleagues' trust, in order to make them feel safe about sharing thoughts, opinions, life events, feelings or whatever each one wanted to share.

It is also true that, independently of "my research", the BAS is part of the academic experience in that particular course and that this seminar always consists in a group pursue of researching and learning from experience. The form "we" is used deliberately to express that I also commit myself to the process and that my experience was also shared with students. To the same extent, students were active participants in the seminar and, for those who wanted, in the research project.

It is arguable that as I was in the role of the teacher, i.e. in a potentially more powerful position, students might feel somehow coerced to participate in the research. This was the reason I did not take any kind of written notes during the sessions and that the demand for students' materials was made after the end of the seminar. Obviously, it is impossible to prove that this complete freedom was always realised by these students but the single thing I am sure about is my

awareness and constant effort to avoid any kind of manipulation. Furthermore, the concept of empowerment also applied to all participants in this process. Moreover, it would not have made any sense to do otherwise. In addition, besides the ethical implications of the double role of teacher and researcher, which will be discussed subsequently, it is important to consider this from the perspective of phenomenology.

As a researcher, I agree with the statement that “it is impossible to imagine observation of the social world without the possibility of social interaction or participation being inherent in that observation” (Cohen, Kahn and Steeves, 2000, p. 64). According to phenomenology, the researcher is part of the research and her or his experience is the means by which he reads reality. The challenge is to develop an awareness that allows the putting in perspective of her or his own experience and observations. It is also important to describe the context and the process in order to decrease the risk of bias (Cohen, Kahn and Steeves, 2000). Thus, I considered myself as a participant who had the responsibility to lead the group through a reflection process, and not just as an aseptic observer. Furthermore, extra care was taken in detailing the whole process. This route encompassed two stages: performing the reflexion on practice with nurses (the BAS period) and collecting data, i.e. receiving the material from nurses and conducting the interviews.

Hence, after finishing the seminar, participants were invited to an in-depth interview to explore analysis and interpretation of concepts. During the seminar, I stated clearly that I would like to work on written narratives, oral recitals and diary notes. However, it was also underlined that any participation was absolutely voluntary and each student could choose what kind of material they would like to submit. Besides this, I wanted to interview volunteer participants after finishing the seminar. Thus an informed consent form was given to each student. Those who would like to take part in such an interview were asked to return the

informed consent form together with a telephone number or e-mail address in order to book the interview. The consent form was returned to my mail box. The same procedure was used for the personal written or audio taped material, with all material, put together with a consent form in a sealed envelope and dropped in my closed mail box.

As described before, 20 written narratives, 10 oral recitals, 11 diaries together with consent forms and 14 contact-forms for interview were received. However, one nurse became seriously ill and dropped out and two did not come to the scheduled appointment. One of them asked to reschedule but did not come. For ethical reasons, I did not ask for rescheduling. The BAS took place between March and July of 2006 and the interviews were booked between September and December, as shown in Table 3.

Table 3 – Schedule of biographic work with nurses

Nurses' Biographic Seminar and Interviews Calendar																	
March to July 2006									August	September	October	November					
Session1	Session2	Session3	Session4	Session5	Session6	Session7	Session8	Session9									
Preparatory work with the group to explain the process and its methodology																	
	Informed consent																
		Production and analysis of oral narratives															
													Production and analysis of written narratives				
														Synthesis and process analysis			
Production of written diary										Individual interviews							



### **Nurses' interview plan**

The interview format was non-directive and unstructured, as the purpose was to explore nurses' analysis of autonomy and the concept of empowerment as they emerged in the course of the Biographic Approach Seminar. Thus, it was not possible to establish an interview plan prior to undertaking a first analysis of written narratives. Nevertheless, some topics to be covered in the interview were identified:

- Concepts and experiences of autonomy and empowerment;
- Nurses' empowering or disempowering attitudes;
- Older people's attitudes towards autonomy and empowerment;

Hence, a first reading of the written narratives was made and some possible questions emerged in order to expand nurses' analysis and interpretation of their experiences. Thus, the aim of the interview was to expand nurses' analysis of their own experiences, rather than to ask for new narrative material. Some examples of the questions that were posed to nurses are:

- During the Biographic Approach Seminar we discussed autonomy and the concept of empowerment and experiences: could you identify what you learnt from this experience?
- Do you consider that anything changed in your daily practice regarding these issues? Can you explore these changes? Tell me more about them...
- What do you consider to be behind nurses' empowering or disempowering attitudes?
- And behind older people's attitudes?
- In your narrative you focused on specific attitudes or situations (to be specified for each nurse) that influence the autonomy and empowerment

processes. Can these attitudes/influences/situations be changed in a positive way? How?

Therefore, each interview was different and built upon each nurse's written narrative. The duration of interviews varied from 30 to 90 minutes.

### **Data gathering**

Subsequently, a long and exhausting task was undertaken transcribing word by word all materials, from audio records and handwritten notes, gathering 476 pages of written data:

- *Nurses' written narratives* – 20 written narratives were collected. These narratives were delivered by students in written form. The documents were digitalized and converted into editable text. No changes were introduced in the data. The only revision done was in order to screen for failures in the digitalization and formatting process.
- *Nurses' oral recitals* – The 10 oral narratives were delivered by students who had accepted to give this kind of data in an audiotape form. The tapes were heard and a word by word transcription was made. No changes were introduced in the data. At some points, question marks may be found in brackets. This means that some words are missing owing to an incomprehensible sound being recorded.
- *Nurses' interviews* – The interviews were captured by a digital recorder with Digital Voice Editor Software. All data files were moved into a personal computer equipped with the same software. Transcription was done without any changes in the data, producing 11 verbatim transcriptions. At some points, question marks may be found in brackets. This means that some words are missing owing to an incomprehensible sound being recorded.

- *Learning diaries* – Reflexive handwritten notes resulting from critical thinking through biographic work were returned by 11 nurses. A word by word transcription of nurses' notes was made. The nurses were free to give only a part or the complete diary. Thus, notes have sequential numbering merely in order to identify each specific piece of work done at a specific moment. As pieces of paper are often not dated, numbering might have no correspondence with chronological sequence. At some points, question marks may be found in brackets. This means that some words are missing owing to an illegible handwriting.

As all data is in Portuguese, a translation into English was made of one example of each kind of material and included in the accompanying material: one oral recital verbatim (Appendix 2), one written narrative (Appendix 3), one diary (Appendix 4) and one interview verbatim (Appendix 5).

### ***3.5.2. Structure of biographic work with patients***

The participation of older people relied also on the biographic approach. According to the initial project proposal, three interviews were planned: two in hospital and one at the patient's home, up to two weeks after discharge. However, after the first five patients were approached, one refused clearly and the other four asked what the purpose of the home interview would be. Hence, it was decided to leave out home visits as I felt that they could seem invasive to patients. Consequently, the third interview was moved to the discharge day.

#### **Patient Interview format**

The interview format was unstructured, as biographic work lies in lived experiences. Non-directive questions were used to the extent necessary to cover the topics envisaged for each interview. However, a plan of each interview was

made, pointing out its particular aims and listing some possible questions, as follows:

### **First Interview**

The focus was on breaking the ice, gaining acquaintance, and starting the issue of autonomy by asking participants to make a narrative of vivid experience of events evidencing autonomy or its absence. The subject of hospitalization would not be brought up. This interview took place on patient's recruitment day (varying from the second to the fourth day of hospital stay). Permission to continue two or three days was asked for. Some possible questions were:

- Is this your first time in hospital?
- How long have you been here?
- How are you feeling now?
- What is the meaning of autonomy to you?
- How have you experienced autonomy throughout your life?
- How important is it to you?
- Tell me about specific situations in which you felt autonomous.
- Tell me about specific situations in which you felt lack of autonomy.

### **Second Interview**

The second interview took place two or three days after the first one and the focus was on empowerment and the decision-making process, asking for a narrative of experienced situations of empowerment and disempowerment. The dialogue was not directly conducted to the issue of hospitalization, but patients often brought it up. Some possible questions were:

- What is the meaning of the word empowerment to you?
- How have you experienced empowerment throughout your life?

- How important is it to you?
- Tell me about specific situations in which you felt empowered.
- Tell me about specific situations in which you felt lack of empowerment.

### **Third Interview**

This interview was as close as possible to discharge, in order to facilitate a free expression of hospitalization experience, without the fear of any penalties from staff. The aim was to explore the narrative of the hospitalization experience, both the recent one and even previous ones, asking patients to select significant narratives related to autonomy and empowerment issues. Some possible questions were:

- Tell me about your latest experience of hospitalization.
- How did you experience autonomy and empowerment?
- Tell me about specific events (from this latest experience or previous ones) related to autonomy or lack of autonomy.
- Tell me about specific events (from this latest experience or previous ones) related to empowerment or lack of it. How did you deal with those situations? How did you feel?
- What might influence the results: patients' own attitudes, nurses' attitudes, other influences...? What could be changed for better in nurses' attitudes or practices? What could be changed for better in patients' attitudes?
- Do you think that anything could be changed for better in hospitalization regarding autonomy and empowerment?

### **Interview participation**

Despite this planning, with specific aims for each interview and a target of 3 interviews per patient, the number of interviews varied from 1 to 4 (Table 4), with duration time between 10 to 30 minutes.

Table 4 – Number of interviews performed per patient

<b>Patient</b>	<b>Number of Interviews</b>
1	1
2	3
3	1
4	4
5	2
6	3
7	1
8	2
9	1
10	1
11	1
12	2
13	2
14	2
15	2
16	2

As stated before, the interview guides included possible questions, as the interaction with each patient was tailored to unique interviews. For most of the time, the sequence was dictated by the patient and the most frequently asked questions were “Could you tell me any moments or situations in your life related

to having power or autonomy? How would you describe your life-story of autonomy?” In many cases, patients’ conversation during the first interview covered all the topics planned to be discussed over the three interviews. Thus, often the second or the third interviews were used to exploring the previous ones, instead of to bringing new topics. Moreover, in the second or third visit, patients often said “I think I did already say everything about it” and, additionally, a few times patients said they would like to talk, but without audio recording. These decisions were absolutely respected, not only for ethical reasons but, furthermore, because it would not make sense to be somehow directive while I was conducting research on older people’s empowerment. Thus, 30 interviews were recorded expressing patients’ lived experiences. It must also be said that, after stopping the audio recording, often patients talked a lot more than for the recorder but, in spite of this being a very rich experience, I could not, for ethical reasons, use these data. Nevertheless my overall impression was that some fear of talking was present; possibly fear of saying something that might influence care in a negative way. The expression “fear of retaliation” was used twice by patients, revealing that freedom of speech is not experienced by everyone.

Collecting data through interviews encompasses many challenges, as documented in the literature, either related to researcher’s ability to conduct the interview, to a participant’s willingness to talk, or to external factors (Wengraf, 2001). In the first place, the environment should be quiet and undisturbed and, as much as possible, familiar to participants. To be in a participant’s familiar place may reduce the differences of power between interviewer and interviewees (Balls, 2009). In the present research, patients were in hospital and I went there to see them. Neither part was really “at home”. As patients were in a ward (which is not always a very quiet place), I looked to select less busy hours (in the afternoon) to minimize the possibility of interruptions. And considering my previous and ongoing experience, I never felt that the “ward environment” brought particular constraints: patients kept on talking, even when someone entered the room.

On the other hand, the use of audio recording equipment may be intimidating just because of the presence of equipment or by the fear of being recorded. Hence, the use of discreet equipment is recommended; namely, a lapel microphone or remote microphone. Nonetheless, whatever equipment is used “researchers should try to make the recording as unobtrusive as possible” (Balls, 2009). In the present research a very small digital recorder with a lapel microphone was used; nevertheless, sometimes patients revealed some fear of talking. This may be due to different reasons. Firstly, to talk to someone one did not know before may be difficult (Salmon, 2007); nevertheless, this reason continued to be valid after stopping the recording.

Secondly, in a one-to-one interview each one has to stand alone with one’s own statements. In group interviews each one is protected by the group with an increased support, encouragement and sense of safety and trust decreasing interviewer power over the participant (Salmon, 2007). Moreover, one-to-one, namely face-to-face, interviewing outcomes depend on perceived status differences between interviewee/interviewer and even though “the interview may be seen as a conversation between two people, the relationship between these two is not equal” (Ryan, Coughlan and Cronin, 2009). Nonetheless, this statement continued to be valid, as was the one before, after stopping the recording.

Hence, the other reason pointed out is related to the fear of being recorded regarding some sensitive issues, the fear of being misinterpreted about delicate topics that could be considered as formal complaints against health professionals or the institution, as, to participate, patients must feel safe regarding research and regarding any eventual consequences on treatment (Ryan, Coughlan and Cronin, 2009). A perceived vulnerability towards health professionals or the health care system may cause some distress and participants may feel the need to be self-protective. Therefore considering my experience in this research I think that the fear of some kind of retaliation was present in some participants. As a participant said off-record “a spoken word goes with the wind, but the written word remains”.



After interviewing, a long period of transcription started, encompassing an added difficulty: often patients almost whispered words and the voice was not loud enough to allow for an easy transcription. Sometimes the same 10 or 20 seconds of conversation had to be listened to over and over again in order to understand it. Nonetheless, some unintelligible words remained and these have been replaced in by question marks in brackets. Here again, I encountered an added difficulty, as patients' oral speech is full of idiomatic regional expressions, more dubious in meaning, more hesitant in fluency. Thus, I tried to be as accurate as possible, knowing that a translation is already an interpretation. As for the nurses' material, all transcription was accomplished in Portuguese and one interview verbatim was translated (Appendix 6).

### **3.6. Ethical issues**

To reflect on ethical issues is an obligation of every researcher and I was concerned to abide by all general ethical principles and by University of Northumbria at Newcastle (UNN) policy. Therefore, special attention was given to the fact that some of the participants were particularly vulnerable persons as these were hospitalized older people.

Ethical critical thinking is important in every stage of the research process, from conceptual work (respecting copyrights, citing correctly and giving credits to authors) to the methodological stage (selecting the most adequate tools, avoiding unnecessary procedures, thinking carefully about the sampling process). Overall is a necessary consistency all along the way, thinking about every step in order to ensure a clean empirical process. Obviously it is necessary, at any time, to make choices and I made mine as follows.

In this research I chose to work separately with a sample of nurses and a sample of older people. Firstly, biographic work requires intensive attention to participants and an immediate analysis which I believe that is not reasonable to do

with both populations at the same time. Furthermore, being a part-time student with a full-time job, it would, therefore, not have been reasonable to believe I could have done the work with both groups simultaneously. And last, but not of least importance, I did not want nurses trying to influence patients, or vice-versa. Moreover, the risk of “contamination” of the researcher’s thinking would have been greater. I wished to understand what was behind each participant’s attitudes, just the way they were. Subsequently, the intersection between nurses’ and older patients’ points of view was planned to be done further on.

Regarding all participants, a free and voluntary participation was ensured, including the right to withdraw at any time, anonymity, privacy, confidentiality, the right to speak freely and to reveal information only to the extent the participant felt comfortable so doing. Any audio recording was the subject of specific consent and would be stopped at any time at the participant’s request. Moreover, audio records, as well as the verbatim and written notes, were kept in a secure place (locked in my office) and would not be available to anyone else, besides the researcher and supervisors. I consider that extra care is necessary when using biographic work, as in this research people are being asked to talk about their private lives and experiences. Furthermore, there were various meetings with each participant. For this reason, at each meeting I revalidated informed consent with the participants, underlining the possibility of dropping out at any time, and assuring them that participation, refusal or withdrawal would not have any implications in academic life (neither rewards nor penalties). In addition, two group sessions were used with nurses to explain the whole process of biographic work and its implications.

Confidentiality was a crucial issue, as in group sessions participants’ lived experiences could be shared. Thus, a collective informed consent and ethical commitment was discussed and formally signed by all participants (researcher included) and a copy was given to each one (Appendix 7). An active effort was

made to avoid judgements by any participant concerning any event or experience narrated by nurses.

There were different sources of data collected with nurses: oral recital (audiotape or audio file), learning diary (handwritten notes), written biographic recital, and interview. Each participant was free to make (or not) any of these contributions.

No pressure was put on nurses to give any data. Each participant signed an informed consent form when they returning personal material (audiotape, diary notes and written recital). This consent was signed in English (Appendix 8) and a copy in Portuguese was given to each nurse (Appendix 9). Before each individual interview a new consent form was signed by nurses. At this point, I chose to use a bilingual form (Appendix 10).

Regarding older patients, I decided to reduce the older people's sample to just one institution and one ward: full attention was given to all patients from that ward during the data collecting period; it also reduced institutional cultural differences as the purpose of the research is not to focus on cultural issues. Adopting this option for the patients' sampling process also solved the ethical issues related to giving time and attention to some older people and not to others: everyone had the same amount of attention. The patient's clinical condition had to be stable, and chatting for one hour not to cause any predictable harm. This evaluation was made by asking a patient's primary nurse a simple question: "According to your knowledge of your patient's condition, do you consider that to chat for up to one hour would cause any possible harm?" If the answer was negative I applied a cognitive assessment tool (Mini Mental State Examination). All older people without cognitive impairment were then invited to participate (cut-off point of 24, as stated by authors).

Hence, in the first interview, informed consent was sought, the aims of the study, the participation implications and the rights to refuse or to drop out without any consequences all being explained (Appendix 11 – English Translation). The

informed consent form for patients was available only in Portuguese (Appendix 12 – Portuguese Form), and large print version were available for the visually impaired (Appendix 13). For illiterate patients (in Portugal, up to 30% of older people cannot read) a nurse was asked to be present as testimony, and to sign at the patient's request; this is a common procedure in Portugal and I used it before. At the end of each interview, permission to continue visiting the participants in hospital was asked for and, in addition, at the beginning of each interview, the consent was revalidated and the permission to make an audio record was sought. Moreover, participants were informed that, at any time, at their request the recording would be stopped. Regarding confidentiality and anonymity, it is important to say that all participants' details were protected, tapes were kept in a locked cabinet in my office and that no names appear in the final report.

Besides participants' consent, the necessary authorizations from the relevant institutions and committees were sought. In accordance with UNN requirements I sent in a Criminal Convictions Certificate (translation in Appendix 14) and obtained the approval of the School Ethics Sub-committee (School of Health, Community and Education Studies – Northumbria University) (Appendix 15). Subsequently, the approval from the Health Superior School Scientific Board - Polytechnic Institute of Setúbal (Portugal) was obtained in order to undertake the research with nurses (Appendix 16), as well as authorisation from the Administration Board and Ethics Committee of Hospital Garcia de Orta, in which the patients' interviews took place (request in Appendix 17, approval in Appendix 18).

Thus, I strongly believe that I made an active effort to abide by Northumbria University's policy and guidelines regarding ethics in research.

### **3.7. Data analysis**

Data analysis was a complex work, due to having various sources of information were (patients and nurses) who produced different materials, as described before. In this study, qualitative data was collected (narratives and interviews). Moreover, the study aim was not to quantify such data or to categorize it, but to interpret it, as the aim was to understand the lived experience of participants (nurses and older patients) regarding a specific phenomenon (autonomy and empowerment) at a particular moment and in a particular place (hospitalized in an acute care setting). Thus, the approach to data was interpretative (i.e. hermeneutic), in order to answer the research question.

As biographic work is an interactive methodology, nurses were invited not only to produce narratives about older people's empowerment in an acute care setting but also to discuss their conclusions. Starting with individual experiences, each one was challenged to analyse his/her understanding of nursing practice in relation to autonomy and empowerment. Throughout the process, participants were encouraged to write a diary including thoughts, feelings, findings, and questions.

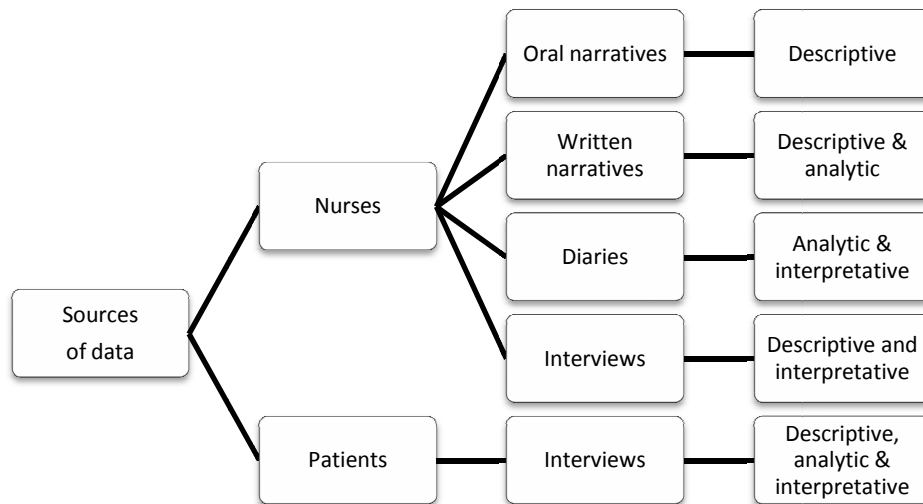
As the BAS progressed in 4 different stages (preparatory, descriptive, analytic and interpretative), a few aspects are relevant to keep in mind regarding data analysis. The preparatory stage included BAS presentation (structure, underlying concepts and method), concept discussion (autonomy and empowerment) and informed consent construction. No data were produced at this point. The descriptive stage included the researcher's oral narrative (a significant contribution to make explicit the researcher's prejudices, according to Gadamer), and participants' oral narratives. In the analytic stage, participants shared feelings about telling their life experiences but judgements or interpretations were not made. The aim was to analyse the experience and the shared histories in order to ask the question: "what did we learn, discover or reveal about autonomy and empowerment by listening to ourselves and to others?" Hence, each participant wrote her personal history and

also her own analysis. The interpretative stage included sharing analysis, and possible interpretations were discussed in small groups (4 nurses). Transferability was also worked out through confrontation in a wider context (the various working places and life experiences of the small group and the large group) of individual ideas and interpretations. Subsequently, the interpretations were shared and explored in individual interviews. In these interviews, the researcher validated with each nurse her own interpretation in order to contribute to credibility.

The material produced by nurses was simultaneously descriptive, analytic and interpretative. In a brief overview I would say that oral narratives were largely descriptive, written narratives were predominantly descriptive but with a significant analytic component, diaries were mostly analytic and interviews were more analytic and interpretative. The reason for this statement is that, in the oral narratives, it is possible to find descriptions of events, something that happened and that the nurses considered relevant. It is also possible to find descriptions of feelings and emotions accompanying these events. It could be stated that the oral narratives answer the questions “what happened?” and “how did I feel?” In the written narrative, the data is full of descriptive material, telling what happened in selected events, but nurses also tried to question the reasons why they acted (or reacted) in a specific way. In the diaries, however, short statements include self-questioning, namely related to the reasons for considering “significant” some selected event, sometimes analysing learning outcomes related to these events. Finally, in the interviews, nurses tried to find the meaning of these events, feelings, learning outcomes. However, there are no closed compartments as all forms of material have all kinds of data (descriptive, analytic and interpretative). Nonetheless, different trends in each kind of material are perceptible, mirroring the different stages of biographic work, as also described in the literature (Josso, 1991, Dominicé *et al.*, 1998, Josso, 2002, Cabete, 2005a, 2008). Regarding patients’ data, since such data came only from interviews, they are predominantly descriptive, but analytic and interpretative material was also founded. As

highlighted on Figure 9, the variety of data made analysis a challenging endeavour.

Figure 9 - Sources of data



With such a variety of sources, the analysis may follow different procedures. Moreover, different steps (or stages) may be considered within the same basic philosophy of analysis.

Earlier in this chapter, I tried to highlight the most significant issues in hermeneutic phenomenology, including its evolution, underpinned by the work of Heidegger and Gadamer, with recent contributions by nurse researchers (Gadamer, 1979, Heidegger, 1984, Guba and Lincoln, 1989, Gadamer, 1994, Koch, 1999, Todres and Wheeler, 2001, Annells, 2006, Koch, 2006, 1994). However, as well as outlining the history of hermeneutics, it is important to state clearly what references I had in mind in pursuing the task in hand.

As I am involved in a story telling endeavour and strongly believe that my own experience is the eyeglass through which I am able to read reality. Nonetheless, this is a challenging process, as it consists in uncovering the underlying meaning

in the words produced by participants, acknowledging the risks of misinterpretation, as no one is always a “perfect reader” or a perfect speaker or writer. As Jasper exemplifies, it may occur that “I never quite say what I mean, and I never quite mean what I say” (2004, p. 13). Hence, it is vital to realize that the outcomes of a hermeneutic study are a possible answer to the research question and not the unique answer to the research question: in the first place, because we cannot take “too simply and straightforwardly the idea that a text is just exactly what it was intended to be in the mind and intention of the author” (Jasper, 2004, p. 13), in the second place, because the same words may have different meanings, depending on the semantic world of the speaker as well as the semantic world of the interpreter (Ricoeur, 2000). Thus, the same text may be understood very differently by different readers, depending on their age, gender, cultural assumptions and beliefs (Jasper, 2004), as well as their own individual life experiences.

Hence, we read data through who we are and, for this reason, it does not make sense to “isolate” our thoughts, to make an “aseptic reading”: even if we would like to do so, it would be unlikely we could achieve this. Thus, the exercise is to look at data through the eyes we have, searching for **a** truth (and not for **the** truth), moving our thoughts from the hermeneutics of faith (I believe this is what the text means) to the hermeneutics of suspicion (does the text really mean this?), in a circular movement between text and interpretation (Gadamer, 1979). Furthermore, it is often difficult to identify where the hermeneutic circle starts: in the text or in the interpretation? And “the answer is neither and both” as

In order to gain an overview of the text in its completeness we must give proper attention to the details and particulars. But we cannot appreciate the significance of these details without the sense of the whole work (Jasper, 2004, p. 21).

Travelling between text and interpretation, through faith and suspicion, the challenge of hermeneutics is to follow one’s trail to produce a contribution to knowledge: an original contribution, as it is a unique one; the understanding of the researcher in her or his uniqueness.



With this referential in mind, data were approached through a series of proceedings in three different stages: nurses' point of view, older patients' point of view and the integration of both, encompassing the researcher's reflexions.

### ***3.7.1. Nurses' understanding of autonomy and empowerment***

This process will lead through progressive steps to an exploration of how nurses understand autonomy and the empowerment process:

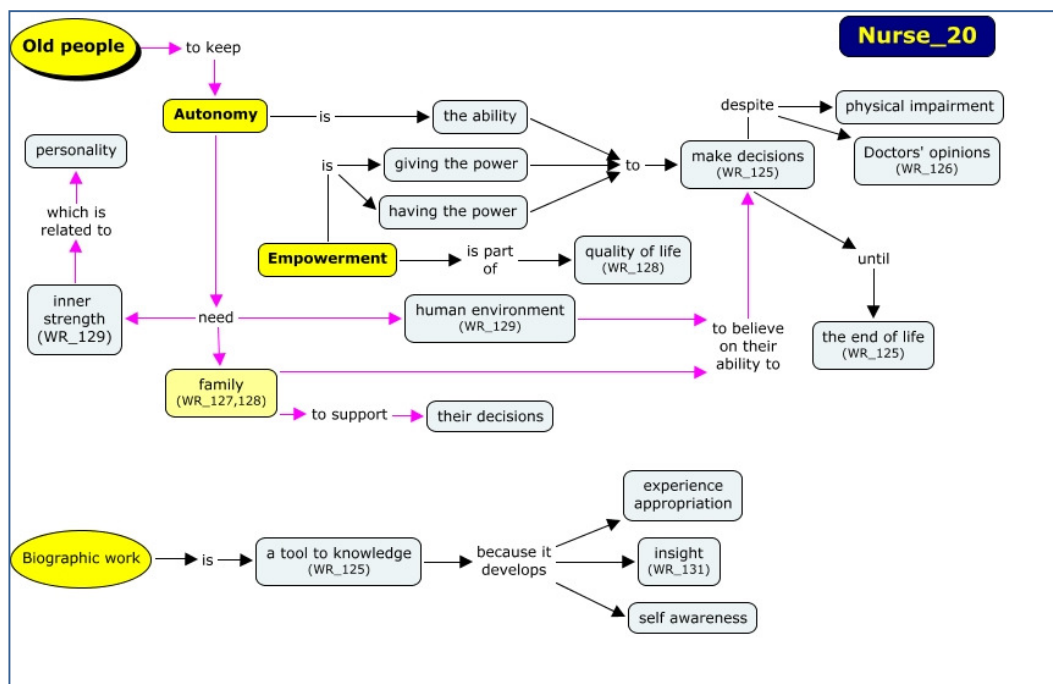
- The hermeneutic analysis of nurses' oral narratives, written narratives, written diaries and interviews;
- The development of a matrix by comparing similarities and differences, structuring the essence of concepts and processes in successive stages starting with oral narratives to create a basic framework, which will be progressively filled by data from the written narratives;
- The creation of a nurses' framework consisting of an interpretation of the previous matrix.

In order to achieve a comprehensive view of nurses' understanding, I read repeatedly all material of each participant, one by one, in order to have an idea of the whole experience. I then started to create a mind map for each nurse's material. I always followed the same order. Namely, I picked the oral narrative of one nurse, and, after reading this verbatim several times, tried to highlight the key issues brought up, the relations between them and the underlying concepts, drawing this by using conceptual maps software. In the second step, I took up the written narrative, read it and went back to the mind map and added new ideas, links, and interpretations. This was repeated with the diary and, finally, with the interview; thus building a multilayer analysis. The whole process was then repeated for each nurse, creating 20 mind maps (Appendix 19).

An example of these maps is shown in Figure 10 (one of the smaller, to fit into the page), describing the thought line of Nurse 20, who only gave a written narrative. Inside the text boxes, there is often some information in brackets that localizes a significant piece of narrative that highlights the concept or the idea indicating the kind of data (Oral Recital – OR; Written Recital – WR; Diary Notes – DN; Interview verbatim – IV), followed by an underscore and a number corresponding to a page number.

Thus, I read the information in Figure 10, starting at the “Old people” box, following the arrows and turning left; this means that, according to Nurse 20, “Old people, to keep autonomy, need inner strength which depends on one’s personality” and an example of this statement may be found on page 129 of the written narratives.

Figure 10 - Mind-map of Nurse 20



The next step was to merge all conceptual maps in order to achieve a global mapping of the main ideas of the group of nurses. The aim in these two steps was not to accomplish an exhaustive categorization but to capture the cornerstones of nurses' understanding. Thus a global map was built up, again using conceptual maps software. As this resultant map is too large to fit into the text, it is also in the Appendices (Appendix 20).

Looking at the mind maps, some themes emerged concerning the concepts of autonomy and empowerment. In the first place, autonomy means "having a mind of one's own", despite physical or mental illness or handicaps, and losing autonomy is being tied to another's will and decisions which, even temporarily, changes dramatically old people's life and behaviour; even highly impaired old people should (and must) have the opportunities to play an active role in the development of their physical, emotional and intellectual skills; moreover, to be autonomous does not rely only on inner strength: it depends more on the human environment; namely, nurses and relatives who often do not pay attention to older people's wishes, as they just decide, assuming they know what is the best for them (where to stay, when to go). On the other hand empowerment is quite an unknown concept to most of the nurses; it does not require "big acts", but small gestures with a purpose and having a great value; nurses recognise that they should and could have done better regarding patients' empowerment. Often nurses do not ask for older persons' opinions and do not give the necessary time and opportunities in order to allow older people to decide, to express feelings, emotions, even in very "small" things such as what to eat or how to dress. Moreover, the lack of time or shortage of nurses is an excuse, because most of the empowerment process does not depend on having time. It is true that empowerment is a difficult and challenging process, but nursing care without empowerment is not full nursing care. The empowerment process can only be possible if nurses consider patients equal in dignity, respect and rights.

After building a global mind map, I went back to the data, following the hermeneutic cycle, in order to describe a comprehensive view of nurses' understanding of autonomy and empowerment.

### ***3.7.2. Patients' understanding of autonomy and empowerment***

The process of data collection with patients was significantly different from the process with nurses: less intensive and less extensive. With some patients, just one appointment took place and with other patients up to four interviews were carried out. Some patients wanted to talk about past experiences and others about present. Some patients wanted to talk about hospitalization in the first interview and others avoid talking too much about it. This was respected, not only to ensure older patients' right to participate or refusal but also because it would be highly inappropriate to be directive in a research about patients' empowerment. Thus, each interview is unique and hardly comparable in structure with the others. Nevertheless, each patient made a rich contribution, sharing her or his own life experiences.

However, it was even harder to translate the patients' interviews than the nurses' material: their speech is not academic but colloquial, full of idiomatic sentences and regionalisms and more than that full of implicit meaning. Often patients took for granted that I understood the implicit meaning of their speech, going on without expressing themselves openly, assuming that "to the wise a word is enough"<sup>6</sup>. And some patients used frequently the expression "you know what I

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<sup>6</sup> The Portuguese corresponding expression in a word-for-word translation would be: '*To the good listener half of the word is enough*'. And often this was the reality: half of a word, half of a sentence, an underlying meaning or a suspension at the end of a sentence.

mean, don't you?" Thus the challenge is trying to be wise enough to uncover the underlying meaning of testimonies in order to produce a reliable interpretation.

Hence, the first task was to read each patient's verbatim interview more than once, trying to find the meaning of each one and its core issues. As with the nurses' material, mental maps were produced, not to achieve an exhaustive categorization but to find a way to organize and present the data (Appendix 21). Thus, the first step consisted in undertaking a hermeneutic analysis of interviews' verbatim, trying to capture the essential structure of patients' experience.

The second level analysis of patients' testimonies was accomplished by developing a matrix comparing similarities and differences between individual structures, building the essence of concepts and processes. This process allowed the construction of a framework mirroring patients' understanding of autonomy and of the empowerment process. A global conceptual map was developed (Appendix 22). In this way, it started to become clear that patients' testimonies covered three topics:

- The meaning of the concepts involved; autonomy, dependency and power and empowerment in the wider context of their lives;
- The experience of ageing and its influence on autonomy and empowerment;
- The experience of being in hospital, both in the present situation and in previous ones.

The following step endeavoured to go towards a more comprehensive model of the issue being studied, by describing patients' understanding through a constant movement between interpretation and data.

### ***3.7.3. Towards a comprehensive understanding***

This step was crucial in data analysis and consisted in merging nurses' and patients' points of view to develop a comprehensive understanding. A comparison between the frameworks of both groups was conducted, highlighting common ideas and underlining differences in order to achieve a global empirical framework. This work was intended to expand the understanding of autonomy and empowerment, leading to a new and deeper understanding of data, raising questions and drawing a new analysis and interpretation.

Finally, through reflection and interpretation, with the contribution of a further literature review, a comprehensive model of autonomy and empowerment will be developed in the discussion chapter, in an attempt to contribute to a better understanding of the concept of autonomy and the empowerment process in the context of nursing care for hospitalized older people. An effort will be made to keep a rigorous step-by-step analysis, being aware of the relevancy to abide by a methodological rigour that ensures reliability and trustworthiness of results.

These sequential steps are considered part of the hermeneutic cycle (Ricoeur, 2000, Cohen et al., 2000) as the researcher performs multiple readings of the data, labels possible meanings, works on data reduction and rewrites data encompassing interpretation. The researcher's purpose in undertaking multiple data reading is to immerse him or herself in data, looking for some initial interpretation leading to possible thematic codification. The next step in hermeneutic analysis is data reduction, reorganizing the data without changing its unique character in order to put together identical topics. Thematic analysis is thereafter performed in order to capture the essential meaning of the data. Finally, the researcher rewrites data, illustrated by participants' contributions (Cohen et al., 2000, Jasper, 2004, Bardin, 2004, Grondin, 1994).

Thus, the object of data analysis, according to the Gadamerian approach, is not the language itself but the meaning behind the statements. Therefore, the effort is to

use the interpreter's experience and awareness to retell a phenomenon, travelling from language to life (Gadamer, 1979). Thus, we are here seeking for an explicit elucidation of the meaning of lived experiences, as the expected outcome is the development of a comprehensive model of autonomy and empowerment that might contribute to a better understanding of nursing care and its implications in the context of hospitalized older people. Obviously, being a phenomenological study, the results will mirror a particular moment in time in a particular cultural, political and social reality. This outcome cannot be generalised to other contexts or other populations: it is a "here and now" picture, a landscape captured in at a certain moment.

## **4. FINDINGS**

To present the findings, firstly data from nurses and patients will be presented separately and, subsequently, the two points of view will be compared and merged in order to outline a global understanding of autonomy and empowerment.

### **4.1. Exploring the nurses' point of view**

The aim of this chapter is to present a comprehensive overview of nurses' lived experience, remaining accurate and reliable to the multiple testimonies collected. The challenge is to draw a global picture, whilst maintaining attention to the details. In reading the nurses' stories, as in reading the script of a play, it became possible to identify the main components: the actors, the scenario and the action.

In the nurses' narratives, the leading actors are older people: these actors are thoroughly described, both through their characters and through their actions. Nurses are also leading actors: they provide testimonies of reported events but they also describe their own professional group. Moreover, there are actors in supporting roles, such as family members: they are not the protagonists but they are needed to determine the course of the story. Other participants appear, such as physicians and other professionals, but they seem to be just walk-on actors, as they appear only a few times.

There is action when empowerment and autonomy happen to be under the spotlight, either because they exist or because they are missing, either because they are enhanced or because they are threatened. Also, as in a movie, time has an important role, as often the story moves backward or forward and action takes place at different ages (childhood memories, nurses' past experiences and the present moment). Finally, our attention may fall on the scenario: in a close-up view it is possible to see hospital and its characteristics and in a zoom-out



movement to look to a wider scenario mirroring society and culture, economic resources and policies.

Thus, it seemed to me that this metaphor makes sense, giving an idea of the different elements and their interactions. However, it is vital to keep in mind that the endeavour to describe each of the elements of the script will never be the complete movie, merely fragments of it, as twenty nurses reported twenty different stories with intersection points (as they are telling the story of their lives related to the empowerment of older people). Thus, my interpretation is one of the possible readings of the twenty interpretations given. Nevertheless, the challenge of describing all these interactive components (actors, action and scenario) is accepted.

#### ***4.1.1. Older people in nurses' life histories***

To paint a portrait of older people from nurses' life histories of how they experience empowerment and what the meaning of autonomy is to them it is necessary to take into account the fact that there is not a unique profile of older people. As I went through the narratives, three different profiles emerged: older people from nurses' childhood memories, older people from professional experience, and nurses' older relatives who had experienced hospitalization.

##### **Older people from nurses' childhood memories**

It is clear that nurses had internalised a concept of old people from their childhood:

The discussion about older people... today in class... made me go back to my childhood and... I remember very well my great-grandmother (N3; OR)

It is very hard to talk about older people without thinking of "our" older people, at least those who are closer to us, like our grandparents. (N7; OR)

Either they were the grandparents, great-grandparents or neighbours, older persons are really present in nurses' script and their image is strong.

I have always had a strong connection to older people and also a great admiration and this is related to my childhood. I was raised by my grandparents in a protective environment...all protection in the world came from my grandparents... In the place we lived there were many old people...I remember many old people, incredible old people... for example Ondina<sup>7</sup>, she was a market vendor and she also took care of a dependent husband... he had a stroke... she was a great woman, she did everything by herself. I also remember an old woman, Alice, she was abandoned by her husband but she worked hard to raise her 3 daughters... she had a sewing machine... and a neighbour he was a basket maker always sat on the floor, legs crossed ... I always admired these old people. (N1; OR)<sup>8</sup>

The image of older people, in this excerpt, brings many ideas about their character: they are hard workers, strong people, admired for their capacity to survive economically and to care for others: Alice abandoned by her husband, Ondina who worked in the market and cared for a dependent husband, and the basket maker. Older people protect sick people (the husband with a stroke) and care for the younger generations (the grandfather who provided “all protection in the world”, and Alice who raised 3 children alone). These people with strong personalities raise admiration (this word is used twice), as they are outstanding, incredible people.

They lived in a farm more than 6km away from other houses... we had a vegetable plot with a stream and everything... and she had such a vitality that she yelled from there to the house to say what we should do or to call us... (...) She was very important in our lives, not only as... life lessons... but because of strength, abilities... with stories and cultural richness... We must learn from them if we have the time to hear, to listen, to look into their eyes, to hear the stories they had to tell about life in other ages, about the difficulties they overcame, I think that we had much to learn from them... I learned a lot from my great-grandmother... she was 98 years old (...) she cared for herself, her haughtiness, carrying always her money in a purse tied with a string to her waist... they didn't trust in banks at that time. (N3; OR)

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<sup>7</sup> The names used are fictitious to preserve participants' anonymity.

<sup>8</sup> The source of data may be found at the end of each citation inside brackets, in capital letters N or P, immediately followed by a number. After the nurse or patient referencing, following a semi-colon, the source of data (OR, WR, DN, IV) is referenced. Thus, (N1; OR) means that the excerpt is from Nurse 1's oral recital.

In the example above, the image described is, again, of a haughty person who worked and ruled the house, owner of her possessions, having vitality, still working on the garden.

These older people raise admiration (“we must learn from them”) because they overcame life’s hardships, they stood on their own feet, managing their life and money. They may be cultural teachers, story-tellers, they are powerful and strong. However, sometimes grandparents are just remembered for their love: because they spoil children thoroughly and because they make grandchildren feel safe and welcomed:

When I was little, every day I went to dinner at my grandparents’ house... and they always had some sweetmeat for me. Some days I went with my grandfather to the farm, he let me play with the chickens and sheep... he had a dog and a horse... they loved me and I loved them all. (N12; WR)

She cared about us all and she was quite a mother-hen that loves to have all its little chicks under her wings. (N13; WR)

In fact, images of childhood memories are strongly imprinted in nurses’ narratives. Older people are described as story-tellers, lucid and healthy, standing on their own feet, with accurate memory and running their own lives. They have wisdom and the marks they leave are everlasting. Many examples of lucid and healthy people are given:

From my personal experience, I keep strong memories of my grandparents. My grandmother had 4 children. She never worked outside the house but she was a very active person. Every Sunday, we went there to lunch and to spend the afternoon... always until she passed away... (...)Her husband, my grandfather was the opposite: very calm, devoted to his readings... every day he went for a walk and to buy the newspaper. He was very lucid; his cognitive skills were very well preserved, with excellent memory and excellent health. He died with 91 years old and he never had visited a doctor. (N13; WR)

Older people were healthy, and it seems that some pride is present in the statement: “he had never visited a doctor”. Furthermore, even when some disease or impairment is present, a positive image remains and there is some emphasis on lucidity and cognitive performance:

My grandfather... that oldie of 93 that despite a little stomach ulcer, little stomach problems, despite a fall and a hip fracture, he walked with a little cane, he's healthy, lucid, lots of stories to tell from his time... Well, you know, so many years that we can't count anymore... and he tells his life with lucidity... I know it because he told ancient histories... lots of wisdom... (...)I think we want them to live forever... they are everlasting... (N7; OR)

I remember an old lady, she was not my grandmother but I called her grandma; she was the grandmother of my godmother and she lived there. I was 5 and she was 90 years old. She was completely blind. I went there often. She was completely lucid, she knew lots of stories and I used to sit close to her and I spent a whole afternoon listening to the stories of kings and princesses and stories of fairy tales. I loved to listen to her. These were very good moments. I remember it with tenderness and joy. (N19; WR)

Strong characters are described: they were wise and independent hard workers keeping their power and autonomy.

I remember very well my grandparents... from my mother's side... grandma was a very strong character... she had authority over their children... she had 17 children. (...) Grandpa travelled a lot and stayed away for long periods of time. When I think of my grandmother I see a very strong and brave women who raised all of her children alone, with love and perseverance, she nourished, educated and supported them. (N9; WR) She was "the lord of the house"... she always "proposed and disposed"; She was the commander in chief to their sons and daughters (...) Grandpa was cute... very thin, tall, completely bald... he had a little box where he kept tobacco... he made his own cigarettes... he was a wise man. (N9; IV)

The authority of grandmother is strong and is described with some "male characteristics" through the expressions such as "the lord of the house" and "commander in chief". This made me look at some details related to gender role. Going back to the N1 testimony, it is interesting to notice that women have names, but men do not:

For example Ondina, she was a market vendor and she also took care of a dependent husband... he had a stroke... she was a great woman, she did everything by herself. I also remember an old woman, Alice, she was abandoned by her husband but she worked hard to raise her 3 daughters... she had a sewing machine... and a neighbour he was a basket maker always seat on the floor, legs crossed ... I always admired these old people. (N1; OR)

Moreover, the man who "had a stroke" does not have a name, nothing else is known about him and no feelings of admiration are noted. Even the basket maker, does not have name or family. It seems that women are the leading actors, and

men just walk-on actors. Looking again at the memories of N7, the grandfather is the “oldie”, with “little stomach problems”, a “little ulcer”, “little cane”, and “he was cute”: she does not say that he is outstanding but that he is “cute”. He did not have perfect health. By contrast, the grandmother is a reference of great value, she is a healthy person and she always ruled her own life.

It looks as if like men and women play different roles and even when both are alive and well the power is owned by women: “he was cute” but “she ruled her own life”: Moving to N13 excerpt, the script is the same: “she was active” and “ruled the house”, keeping control over family, but “he was the opposite: very calm devoted to his readings”. It seems that man do not have power at home: home is women’s domain. Furthermore, in the N9 example, the words are similar “he was cute, travelled a lot and made his own cigarettes”, but “she had 17 children, ruled the house and the family” almost like an army. Finally, men earned the money outside the house, while women stayed at home, ruling the house over a lifetime. At the end, when they are retired, they might not have a role anymore. After all, as N3 says, it seems that we had a matriarchal society:

(...) as an example... she was the matriarch of the family... nowadays in our society this is only in gypsy culture, but my great-grandmother took all decisions... she decided everything in the family and no one would ever dare to question... she decided and full stop! (N3; OR)

Women’s power is a topic to be discussed later. Nonetheless it is necessary to keep in mind that all participant nurses were women; thus, it might be a feminine script.

From these examples, it might be said that the portrait of older people from the nurses’ childhoods shows some significant characteristics:

- They were hard workers and they worked until they died;
- They overcame difficulties in life to raise a large number of children;
- They helped to raise grandchildren;

- They cared for the sick;
- They were protective for younger generations;
- They ruled their lives, managed their money, they took all the decisions they wanted to; no one would dare to interfere with their decisions;
- They were cultural teachers and good story-tellers;
- They were charming and welcoming;
- They were cognitively well, having a good memory and lucidity;
- They were healthy and even if some impairment was there they were not considered as a social or a family burden.

This is quite a perfect image but it seems almost too good to be true. It is not a surprise that nurses consider these memories as examples to follow, describing admiration and respect, saying that younger generations should learn from them and that they should be everlasting. These people apparently did not need empowerment because they had control over of their lives, their decisions, their money; they had the authority to rule the family. They were autonomous, as they made decisions and they made things happen. However, even healthy people may become ill, and eventually have to go into hospital at some point. Thus, I looked again at the narratives:

Something that touched me a lot was the death of my grandparents, those who raised me. My grandfather walked out one day to work and never came back... I was 13 years old and he died suddenly... my grandmother also died a few years later, due to an embolism. These were significant experiences in my life. (N1; OR\_1) They both left one day to the hospital and never came back. (N1; WR)

She died at 98 years old of age, following a fall and a fracture; the surgery didn't go very well, I do not remember well, and she got respiratory infection and that's it! (N3; OR\_11) She controlled the family and all things, she was the matriarch and she had her empowerment...she died at 98; she was never in a hospital before. (N3; WR)

These stories seem to tell us that powerful people go to hospital and do not come back. The matriarchs, the hard workers, those who controlled their families and

protected everyone just disappear after hospital admission. Nothing is known about hospital: just that many people go there and die. Nothing is known about what happened to the power of the powerful. Some people just vanish from narratives. When Nurse 11 says “At 81 my grandmother was widowed and decided to move to my aunt’s house...” (N11\_WR) she means that her grandfather died. But his story is absent. And sometimes it looks as if older people are fading away: “My grandmother... she was very powerful, always looking after us... but she was a lady and... I miss her.” (N7; OR). Further than this, there are no details about what happened to her. It looks as if there is no end to this story. Moreover, death is reported briefly: a few words, a few details, no pride, no admiration related to those who died in hospital.

She died at 72. One day she was cooking the lunch and she said that she was not feeling well. She went to the hospital and died 2 days later of a stroke. (N13; WR)

In N1’s words, some disappointment seems to be present: those who “gave me all the protection in the world (...) left home and never came back”. The expression used is “left home” and this expression in Portuguese also means “abandoned”. The same nurse that often uses the word “admiration” describing her grandparents seems to have felt abandoned. Only those who died at home are remembered with pride:

My grandfather, he was very fond of reading and he died [at home] in the way he would like to, at 91 years old. (N7; OR)

Grandma Mary died [at home] of a heart attack. She was so sweet, with very white skin, so thin, her hair in a plait, like in a fairy tale. I’ll always remember her (N12; WR)

One night he went to sleep and on the next day he didn’t wake up... my aunt went for him... and he was dead, in his sleeping position... I think I would like to die like this... he died as he lived... with tranquillity. And that’s it... my older ones! (N13; OR)

The sweet grandmother and the two grandfathers who died in their sleep will always be remembered, are examples to follow, they inspire pride and admiration. Thus, it looks as if hospital is a place to avoid.

### **Older people from nurses' professional experience**

The way nurses describe older patients in hospital seems to be completely different from the way they describe older people from childhood memories; it mirrors an intersection of social myths about ageing and the observation of pain and lost dignity:

How is it to be old in a hospital? Day and night shifts are witnesses of long hours observing those “looking old” people, those with a face wrinkled by time and pain. It is a long list of medications to take for the rest of one’s life, it is to decide what to buy with the retirement payment: food or medication because they cannot fit both into their budget. It is a dry and wrinkled body lying down for hours on a 2 inch mattress litter in an emergency corridor (...) I would like that “Le grand final”<sup>9</sup> would have more dignity: I would like that the older patient who says goodbye to life as we know it, those who fight in the hospital, could do it with some more dignity. (N5; DN)

Older people in this image look like people who have lost everything: youth, health, money, family and well-being. Moreover, nobody cares about what is happening to them, they seem to stay in the corridor for hours. The older patient is described as a face and a body wrinkled by time, but mostly as suffering resulting from physical pain and poverty. The image “a dry and wrinkled body lying down for hours on a 2 inch mattress litter in an emergency corridor” is an image of abandonment, of powerlessness and even negligence. And the words of N5 mirror indignation about this lack of dignity in what she calls the “big ending”.

This is an image that it is not pleasant to see and it is easy to understand why another ending to this movie would be much more appropriate: “This is the image that is waiting for us all. (...) How would I like that it would be? (...) Just with more dignity” (N5; DN). As N5 says, after a long life of achievements, of experience, older people deserve a better ending, perhaps the ending that the

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<sup>9</sup> Excerpt written in French in nurse’s manuscript.



nurses would like to have for themselves. But there is more in the picture of older people besides dignity lost and abandonment.

In my experience, over 11 years as a nurse caring for older people, I would say that being old is to be frail, dependent, often abandoned by family in the most complete loneliness. Health professionals see them as powerless, without the necessary skills to make decisions on their own. Family assumes decisions. Many times they are treated like helpless children or like the cute hundred-year granny. We do not have big life expectations due to illness. (N7; DN)

The picture again is abandonment, powerlessness, dependency, loneliness and impairment. Frail people are divided between the opposing images of a helpless child or a cute white-haired oldie; both situations include someone that is not able to make her or his own decisions, someone that we must protect but of whom we do not have many expectations. It is a paternalistic professional view: they are frail as they have lost strength, health, will and, sometimes, even family and we are the ones who have made the beneficent commitment to help people. If the family is absent, it looks as if only nurses remain to make decisions. Again, myths of frailty and dependency are present. In the diary of N10, a very short statement says the same thing:

In my professional experience, what is it to be old? It is to be a child... is to be frail. We must do everything on their behalf. (N10; DN)

So they are like children (thus, they do not have the necessary knowledge to decide what the best for their health and life is), they are frail (thus, they do not have the strength or the skills to accomplish or to achieve anything) and nurses must do everything on their behalf. Again, dependency assumes a relevant role: older people may have the knowledge (as the grandparents of childhood had) but this seems to be useless, as the strength is gone.

To be old is to have a background that gives wisdom but without the energy to accomplish life projects. It's having lots of disabling diseases. It is to need permanently someone to help. (N11; DN)

It is the connection between "to do" and "to be" that mirrors nurses' concept of autonomy. Likewise, older people always need somebody else to help them. It

looks as if physical abilities are an absolute precondition for dignity or autonomy.

N9 also corroborates this idea:

Elderly patients in hospital... They are frail because they are sick, they feel humiliated without the strength or the skills they had before. They remind us nostalgically of lost youth and health. And they need to feel hope of recovery in order not to feel as a burden. (N9; DN)

Thus, the praise, admiration and respect described in childhood memories seem to be focused not on people but on their physical performance. This is an image that nurses do not like to see: a nostalgic reminder that everybody will lose physical strength. Another issue in this testimony is represented by the word “burden”. The common myth about older people, that they are a social and a family burden, is here presented as one of the patient’s fears. To be a burden is the antipodes of independence: it is the opposite of the older grandmother that rules and commands the house and the family, works in the fields and raises the children.

The relationship with the family is also part of the portrait of hospitalized older people, more by its absence than by its presence: nurses describe family abandonment leading to loneliness (as N7 says above), or even a family that is present but does not wish to take their relatives home:

End of life usually happens in a nursing home or in a hospital bed with the family praying not to take them home. (...) Some more dignity was needed. (N16; DN)

Family issues will be developed later, the focus here being on the way that nurses think patients feel: afraid to be a burden to the family, and afraid to be abandoned. And the family, whenever it is present, seems to assume decisions or at least tries to do so. It looks in nurses’ narratives as if the decision-makers are everyone else but the patients: family, nurses, attendants, doctors or just routine, all have more power over the patient’s life decisions than the patient herself or himself.

Once I was with an old lady (she had a severe condition and she knew she was dying)... I was taking care of her and she asked me to take off all that stuff... it was unbearable to her. And she stated clearly that she didn’t want CPR... and doctors were aware of it (...) and in the meanwhile she stopped... and everybody knew that there wasn’t any possibility of survival, and she also was very aware of that... and in the meanwhile she stopped and the doctors came immediately and

started CPR... it's something... it looks that it is automatic... mechanical... and I even argued with the doctor: "But doctor she didn't want to have CPR" ... but we kept on for over one hour with more this and that... needles here and there and everywhere... I felt revolted, shocked... We all knew and we all complied...why couldn't she have died peacefully? (N9; OR)

This is one example where the patient seems to vanish and just a body (owned by the hospital) remains. Patients' will is ignored and routine is stronger. This nurse even uses the word "automatic", i.e. action without deliberation, without critical thinking. And even when someone raises a question, the action continues; even those who raised the question feel powerless to change the course of things, either because doctors' power is stronger or because routine is deeply printed under everybody's skin and there are rules to be obeyed.

In hospital, they face fear of pain, of death, of separation from family and friends. To older people, to be in hospital may be to live with huge doses of anxiety. It is to deal with a set of rules hard to adapt to. (N4; DN)

Thus, this is a portrait of older people contrasting sharply with the description of older people from nurses' childhood memories. Two opposite characters are described. On the one side, the hard workers who worked until they died, those who assumed the command of a large family, those who raised a large number of children and helped to raise grandchildren. They were special people for their children and grandchildren. On the other side, the older people in hospital: they do not work, they lose their voice, and they do not even take decisions regarding their own lives, largely because they do not even have opportunities to make choices. Even when they do make decisions, nobody seems to listen.

The family seems very absent, considering them as a burden. Moreover, the older people from nurses' childhood memories were never sick; they helped to care for other sick people but these in hospital need to be cared for. While the first group were cultural teachers, the second do not have anybody who is interested in their stories. In Table 5, some of these contrasts are summarized, showing the main characteristics of these two groups of older people in nurses' life histories.

Table 5 - Comparing two profiles of older people in nurses' life histories

Older people from nurses' childhood	Older people from nurses' professional experience
Hard workers	Lay in a bed and lost physical strength
Had a large family	Family is quite absent
Helped to care for younger generations	Family is not willing to care for them
Care for others	Need care
Ruled their lives	Obey to hospital rules
Made their own choices	Do not have opportunities to make choices
Their decisions were respected	Their decisions are ignored
Cultural teachers, story-tellers	Family burden

There is a tension between these two opposite images of older people: the healthy grandparents versus the older patients in hospital (almost described as life remains), whose life expectations are not seen by nurses as significant. These are different populations as they are not connected at all: they are in different places (home versus hospital), at different moments (distant past versus recent past memories) and with different relations to nurses (family and loved ones versus clients and strangers).

### **When nurses are the family of hospitalized older people**

Looking again at the recitals, it is possible to identify a third group of older people: those who in the recent past happened to be nurses' loved ones (parents, in-laws or grandparents) in hospital, those nurses' relatives who became ill, went to hospital, became dependent, and were cared for by other nurses. In this situation, the tension becomes more visible, as nurses are not children anymore: they are adults, health professionals having expectations regarding care towards their loved ones. Their histories mirror a third picture of older people substantially

different from the previous ones. One of the issues brought up is that nurses need to keep caring for their relatives in hospital:

About four years ago, my mother was in a coma for six days and I believe that one of the biggest helps to her was that I never stop talking to her, every day and every time. (N2; WR) Nurses had good behaviour... great behaviour. They let us always stay with my mother, my sister came from Germany, because they told us she didn't have big chances to survive... and all the time that my sister was here she cared for her, they let her in... and let it her give her bath... she was there in the morning and I was in the afternoon after my shift... I think that because of this my mother succeeded to get out from the coma... she was in a severe hiponatremia... and they were saying all the time that she wouldn't make it. But I'm sure that bathing, massaging, the communication... all of this was very important and nurses let us always be there and this is very important to patients in a coma or at the end of life... (N2; IV) It was a significant experience that I had with older people was with my mother, she is already an old lady, and she was in a coma... in the hospital where I worked as a nurse. (N2; OR)

In this excerpt, a few things captured my attention. In the first place, the importance given to care being provided by significant carers (the daughters); namely, physical care and communication. In the second place, the sense of gratification, as this nurse believes that family care was decisive for the patient's well-being. Besides the acknowledgment of the importance of family participation in care it seems that this possibility is also unusual, otherwise it would probably not have been reported or named as great behaviour, the expression "they let us stay there" sees it as an exception, not as a part of the common work of nurses. So, as family members, participant nurses need to be there, but as nurses they do not expect this presence as being integrated into health care. However, nurses also report their difficulties as family members:

I do remember particularly the experience with my father-in-law, he had a lung cancer and I, as the only health professional in the family, I was the one who followed him from the beginning, from diagnostic procedures, to treatments, in the several admissions to hospital where he was due to... to respiratory difficulties (...) and I was there when he died. (...) And I also remember that often I had to run away, in spite of being there with him, and so, I was with him in treatments, and in several hospitalizations and I remember that I often felt... I had to run away... I had really to run away from that situation of facing someone... that I knew was leaving us... I loved him and he was going away... because I'm

also human and I couldn't see him like that... someone that... aware and awake until the end. (N7; OR)

Sometimes, as N7 says, it may be unbearable to keep up with a much-loved person that might be dying or is in great suffering. It is the conflicting feelings "I want to be here and I have to be here because I love him and because I do not want to leave him alone" and "I can't be here because I can't take it anymore", a disturbing contradiction that this nurse acknowledges in herself and which makes her say "I'm also human". Listening to this excerpt, another statement seems to be present, underneath these words: "even if I'm a nurse, I do have feelings..." As if an excuse was needed, as if she felt guilty for not being able to accomplish the job of "full-time carer" with the increased family expectations because she is the only nurse in the family, thus, she surely should be able to provide care easily. This internal conflict regarding personal feelings and social expectations of the perfect and ever-present family nurse is translated into her written narrative:

It is a whirl of feelings in a mix of duty, responsibility, because we are people too, we have our own feelings as human beings (...) and we care not as nurses but just as ordinary people, with feelings jumping out of one's skin. (N7; WR)

However, besides the family topic, there is another issue in these two examples: patients keep fighting in spite the prognosis. The mother of N2 left coma and went home (against nurses' and doctors' predictions) and the father-in-law of N7 who "managed to live two years instead of two months" (N7; OR). Here again, is the profile of "the fighter" as in childhood memories. Nevertheless, these older people were not alone, as other patients in hospital seem to be. This is not the powerless patient waiting for death: it is the patient who has a family and who wants to keep on living.

But, to nurses, being in the position of a family member brings more than the need to deal with inner feelings: it may be the start of critical thinking regarding care:

I did already have quite long experience with older patients... and sometimes we know they are suffering, but to us they are a patient and that's all... and by that time if I had an agitated patient, I didn't have the tiniest doubt to tie him, to tie them, their hands... so they couldn't touch the tubing... and when I came in [to

the hospital unit] and saw my father with restraints...I was... really... well I could have beaten everybody!... I could have beaten all of those people... Only when I saw my father immobilized I did realize... They told me he had an agitated night... Only in that moment I realized what restraints are... (...) It did hurt me... a lot [she starts crying]... I used to do it and he was a patient just like the ones I had to care for... but this one was my father. Today, I do not do this anymore... I realized... Today I don't use restraints anymore like I did before [she keeps crying] ... and it doesn't matter that my colleagues call me Mother Teresa of Calcutta... [Recording stopped by nurse request and continued a few minutes later] In my shift, no more restraints are used. I started to think what other patients and other families feel... And I do not consider myself as a cold person before... but I realized how it is to be like that. (N8; OR)

This nurse performs an accurate self-assessment: her previous attitudes towards older people reveal not much attention being given (they are just patients), quite automatic behaviours (she did not ever have a doubt about using restraints on a patient like that) and disempowering attitudes (the use of restraints). However, at that moment when she sees the same attitudes expressed towards her father, she is shocked as she realizes how much disempowerment and indignity have resulted. Furthermore, regardless of the discussion over the use of restraints, the point is that, even though she admits that she used to employ these, somehow she expected that nurses would behave differently towards her father. Thus, it seems that what was right turned out to be wrong: the routine is questioned. Now her eyes see reality in a different way and her behaviour changed, following this new awareness. However, other kinds of reactions are also reported by nurses:

My grandfather was a farmer 87 years old that for the first time in his life was ill and hospitalized. (...) He had cancer of the rectum, had surgery and he stayed in hospital longer than expected. It was a very difficult time for him. Firstly, because they took his false teeth... but also, due to his pronunciation, nurses did not understand him... he was labelled as confused and they gave him sedatives... We started to find it weird that he was in such apathy, and so sleepy. Our family talked to the health team and the problem was sorted out. But I understood that he felt threatened in his dignity, in his freedom and in his will. He used to say to me: "My dear, why do I have to bath every day? They take all my clothes, and let me naked just covered with a bed sheet... then it's a rush to shower and they rub me as if I was too dirty. They give me orders and they do not listen to what I have to say. They don't even look at me». I tried to mitigate some issues saying that the ward was full and that staff was short (...) He began to look depressed, he stopped walking, and didn't feed himself anymore... and got even more depressed...He was sad and so was I. (...) When we went home he decided what

he wanted to eat (...) he refused to go to physiotherapy and started exercising at home, all by himself. And he did recover. His joy was also my joy (...) and today I do understand that when he recovered the power to rule his life he also succeeded in recovering physically. (N14; WR)

Despite this being quite a long citation I considered it important to transcribe it in order to keep the overall scenario as several interpretations may be considered in this testimony. It is clear in this excerpt that N14 became aware that it is vital to listen to patients and to meet their real needs, instead of just working routinely. It is obvious to her that “to shower and quickly rub all patients” is disempowering care and that she did not like it when it happened to her grandfather. However, she does not evidence the indignation of the previous example: by contrast, she tries to give her grandfather some excuses for the nurses’ behaviour (shortage of nurses relative to a high number of patients). And, even if the family talked to nurses about sedatives, she did not question colleagues about the hygiene and privacy issues. On the contrary, she justifies nurses’ behaviour. Possibly “to leave a patient almost naked and rub him as if he was too dirty” without giving attention or opportunity to make choices, is not seen as being as wrong as sedation. Or there is some fear to raise questions in a ward where this nurse is not a nurse but a visitor. As family members, nurses are not always able to claim dignity and to stand up for patients’ empowerment, perhaps because they do not have enough courage to do so or because they do not want to confront their colleagues.

Going back again to the patient’s personality, it is possible to see that this actor fits into “the fighter profile”: the functional impairment acquired in hospital is recovered just by his inner strength and without medical support or hospital care. He recovered his lost empowerment and autonomy. Despite some submission to hospital routines, he managed to recover the control over his life, to make his own choices, and these choices were respected by the family. This testimony describes some characteristics of the powerless patient’s profile as described by nurses: the patient in a bed, with physical impairment, the one who needs care, the one who is deprived of opportunities to make choices, whose decisions are ignored and who

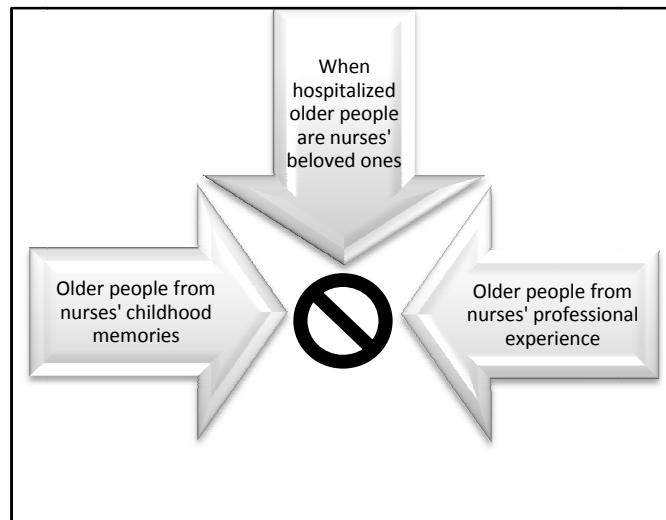


obeys to hospital rules. It is interesting to notice that neither does this patient fight hospital routines nor do his family do anything besides trying to justify professionals' disempowering behaviour. They both accept the situation. The fight to regain autonomy occurs after hospital discharge, in the home environment.

Hence, according to the analysis made so far, three profiles of older people emerge from nurses' narratives (as illustrated on Figure 11):

- On one side: older people from nurses' childhoods; the empowered older people with control over environment, over family and over health;
- On the opposite side: disempowered hospitalized older people from nurses' professional experience;
- And then a third group: nurses' loved ones that lived and made visible the tension resulting from confronting these two sides of experience.

Figure 11 - Older people in nurses' narratives



Thus, when older people in hospital are nurses' relatives, some contradictions emerge: the empowered become submissive, the routine is questioned, the ethical

issues of self-determination are raised and the healthy and autonomous person struggles to survive and to keep self-respect. In addition, nurses' eyes capture pictures of threatened empowerment and even of inhumanity and their feelings are contradictory: to explain or to apologise for colleagues' behaviour or to feel anger and to try to change things. Likewise, when nurses are in the role of family carers their testimonies are divided between the wish to care, associated to the recognition of the unquestionable value of family care, and the burden of being a nurse in their own family. This feeling is associated with the family's expectations: that if there is a nurse in the family she should take the responsibility for the patient as well as take care of the entire family's needs. And this sometimes seems to be an unbearable task.

Hence it could be said that the pre-understanding of the older persons that nurses bring in relation to the acute hospital context is quite negative. Firstly, older people from nurses' childhood memories go to hospital to die. Nurses express pride and admiration for their relatives who managed health issues at home, as well as for those who died at home. Conversely, those who died at hospital are not praised or admired. Secondly, on nurses' professional experience, the image of hospitalized older people reflects powerlessness, autonomy loss, abandonment, dependency and dignity loss. Older people portrayed in acute care are submissive and do not participate in care or in decision-making. Finally, this pre-understanding is confirmed whenever hospitalized older people are nurses' relatives, the only difference being in the fact that nurses became aware of a situation of dependency and powerlessness that does not make sense. Hence, even their fighter older relatives became trapped by hospital rules and nurses' power, feeling disempowered and losing autonomy. Thus acute care seems to be described as a deleterious environment to older people.

#### **4.1.2. What is autonomy?**

Through the testimonies cited so far, the meaning nurses give to autonomy is clearly related to physical functioning and to decision-making skills. Older people from nurses' childhood memories are described as autonomous to the extent they rule their own lives, not depending on anyone either to survive or to care for them. In addition, autonomous older people take care of other family members. But in a second approach to data it is possible to see some differences between the discourse about autonomy and the underlying meaning of autonomy in reported stories. Whenever nurses write reflexive notes in their diaries about the meaning of the word autonomy it could be stated that the core word is freedom:

To be autonomous is to be free in decision-making... (N4; DN)

The meaning of autonomy in nursing care... To me it means to give the other person the freedom, the freedom to decide by himself, the freedom to share feelings (...) the freedom to speak and the respect regarding those decisions, mutual respect between patients and nurses. (N1; DN)

What is autonomy? My first thought was: the aim of nursing care is to help the other person to do what they would like to... (N6; DN)

Thus, autonomy is described as freedom to make decisions, freedom to share feelings, freedom to speak as well as the need to have those decisions respected. Functional performance does not seem to be a core concern. However, when nurses report their clinical experience, the concept of autonomy is focused on functional performance:

Autonomy means to me to do without help, to have one's initiative, knowledge and to take the risks. (N11; DN)

He had almost completely lost his autonomy, namely regarding his own personal hygiene care, to dress himself, to walk, but he didn't lose it completely as he succeeded to overcome impairment (N17; WR)

The focus seems to be on "to do without help"; hence, it is assumed to be lost whenever physical impairment occurs: Nurse 17 states that autonomy is almost lost, namely in activities of daily living, as the patient could not leave the bed. Moreover, she says that the patient did not lose autonomy completely because he

overcame physical impairment. Thus, autonomy is described as independence: to perform self-care or to be able to overcome physical limitations.

Moreover, the examples cited so far have shown older people in hospital often being ignored by nurses, by physicians, and even by their families. Everyone seems to act on their behalf, even though nobody was asked to do so. Also there are no big expectations regarding the autonomy of hospitalized older people:

Well, about autonomy... I really don't remember so autonomous elderly... (N7; OR)

Autonomy in older age is permanently threatened as well as self-determination. To be old is to be powerless and ignored in decision-making. (...) regrettably nurses often have bad practice, leading to older people's confusion, rage, reduced self-esteem and sense of integrity. (N4; DN)

Thus, it is acknowledged that besides not having expectations, nurses undervalue patients' possibilities and do not assess the potential of each individual. This is considered by this nurse as being bad clinical practice. Thus, it seems that since older people do not perform all tasks by themselves it is considered natural that autonomy is lost.

However, a decreased autonomy is also associated with some health conditions that might influence physical performance:

I work in a medical ward that has a high prevalence of stroke patients. I face daily these situations where autonomy is seriously threatened, in some people more than others, depending on how severe the stroke is. Besides, losing self-care autonomy they often even have limitations in communication skills, they have speech disorders, they can't make a sentence or even articulate words or are even aphasic... or they are so depressed that they don't want to express their will anymore. (N8; WR)

In the example above, it seems that autonomy is considered the opposite of dependency, namely physical dependency. But besides this, there is also patients' ability orally to put their will into words: to be able to make a sentence or to be willing to do so. Hence, nurses report the lack of autonomy mostly associated with physical impairment or communication difficulties and it seems that it is

easier to assess patients' autonomy by its absence than by its presence. Nonetheless the positive view is also present:

I met a patient, a woman of 103 years old... I was keen to see her. She decided to have a surgery... it was a minor thing... I do not remember very well what the surgery was about... But she had all her mental skills; it was a short stay... The surgery did not interfere with her life routines... she decided to do it because she wanted... she left hospital on foot... Of course, in hospital we are not allowed to do all we want as we are outside our environment... but she decided to come and she left as she was before. (N6; OR)

In this excerpt, some particularities captured my attention. In the first place, the patient's extreme age (103 years old) that awakes some curiosity and some surprise regarding mental and physical performance: "she had all her mental skills" and "she left hospital on her foot" the same way she came in. However, as far as decision-making is concerned, it looks as if this nurse is saying that it is remarkable that someone at this age decided to have surgery. Thus, it is admitted that autonomy exists even in very old people: "she decided to do it because she wanted to." So, apparently, it is possible to come to hospital and to go home in a short period of time without changing one's routines. However, to some extent, in this example the issue of expectations is also present: this lady goes beyond the nurse's expectations regarding autonomy and that is the reason for the nurse's surprise.

Expectations seem to be something relevant to the way nurses look at older people. The previous example reported a situation that exceeded the nurses' expectation but sometimes nurses do not have big expectations regarding older people's lives. And this may lead to the assumption that it is useless to invest in nursing care:

There is one side of me that makes me question if I have a 20 year old patient and another one of 80... I think of recovery possibilities... and one has lived a lot and the other one not... I think that it might not be fair... but will the 80 year old have the same life expectations... should we invest in the same way?... one day more, one day left... that person will die anyway! I don't know if you understand what I mean... it is not dignifying to think like this... I think that anyone has the right to live and if it were my mother or my father I would like that the possible and the impossible were done in order to save them... but these are not... and when I

think in a colder way why should we spend and invest in somebody 80 years old and with a cancer... why don't they go to palliative care? (N8; OR)

This excerpt suggests that by the simple fact of being old, some patients might not have the same care, the same investment, as this reasoning seems to be based upon average life expectation. In addition, the argument is based on illness and recovery possibilities, i.e. focused on disease and not on persons. However when N8 thinks of particular people (namely, her mother and father) the argument does not make sense anymore. Thus, it seems to be a biomedical focus, instead of a human care focus, with little expectation regarding older patients and their autonomy in acute care. Moreover, according to some nurses, family members may also share this point of view:

Some time ago an old uncle... my father's uncle... was ill and his sons and daughters were already preparing his funeral... and then my parents took him to his home town, to the hospital and he was treated and did recover. But the look in his eyes did change... After that, well... he quitted... he had 6 strokes, and deteriorated a lot... and finally passed away... Once in a while, I helped my mother to take care of him... and I'll always remember the look of good-bye in his eyes... (N9; OR)

In this example, a nurse says that sometimes a family also has short expectations regarding patient's life and that this attitude has a negative effect on older patients. The outcome here was a disempowering effect: the patient quitted living. Conversely, when someone believed and provided adequate care, some recovery happened. Arguably, if expectations are low, the investment in care and in promoting autonomy and empowerment will also be low. Further, in many situations decision-making is not a possibility for the patient: either health professionals or family members decide what to do. And if the decision-making possibility is non-existent, autonomy is impaired:

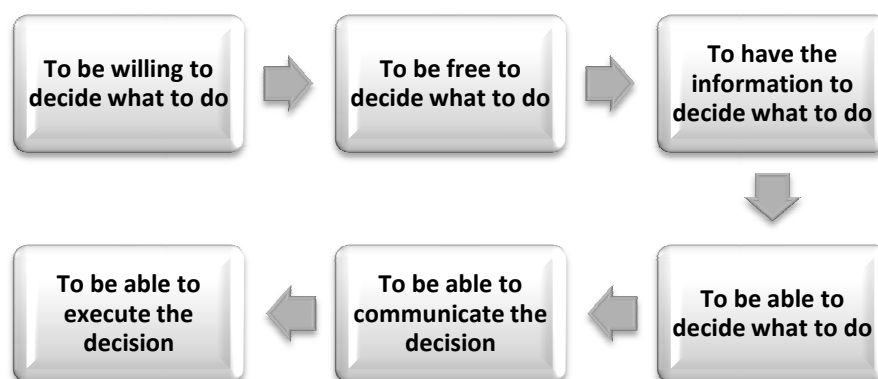
Regarding autonomy...it always upset me that a patient is admitted in hospital and is not allowed to... Not being able to... well... to know what they [health professionals] are going to do to him [to the patient]... I think it is very important to give people the information, always the information in order to... to be aware. Autonomy is really that, to be able to chose, and to have the tools to be able to chose this or that (...) Often older people do not understand what the point of the treatment is, and often they have to decide who is going to decide on their

behalf...I think that autonomy may also be considered like that: to give another person the power to decide on their behalf. (N7; IV)

To this nurse, information seems to be a precondition of autonomy as without information patients do not understand what is happening to them and, as a result, their decision-making is limited. In this particular testimony, there is a concern regarding decision-making: the patient must be able to decide what she or he wants or who is going to decide for her or him.

In summary, nurses say that autonomy relies on a patient's will, freedom and information, and on the necessary skills to communicate a decision and to perform an action (Figure 12). Thus, there are the preconditions to the decision (the will, the freedom and the information), the decision and the action (to inform and to do).

Figure 12 – Nurses' concept of autonomy



All these dimensions rely on cognitive functioning but other links are also described:

- To be willing to decide: is related to emotional status (depressed patients may lose the will to decide), to family and/or health professionals' expectations;

- To have the freedom to decide: depends on a respectful attitude from family and/or health professionals; it includes being given opportunities; furthermore, it requires family and nurses to have positive expectations regarding older people's autonomy and skills;
- To have the information: is conditioned by the access to information and depends on health professionals' active action;
- To decide: either to make a decision or to delegate it to someone else;
- To communicate decisions: depends on communication skills and on a receptive attitude from carers;
- To be able to do: depends on physical skills and/or on a supportive environment and when the action is to be done by other persons (nurses or physicians) depends on a respectful attitude and willingness to enact patients' decisions.

It is very striking that nurses' descriptions emphasise, in first place, the action dimensions (to be able to do and to be able to communicate), particularly in the narrative material (in the oral and written recitals). The decision and its preconditions are more present in the diary and interviews, in which nurses are asked to analyse their lived events. Thus, it looks as if in their daily action, nurses are focused on patient's functional performance. However, when nurses are invited to reflect about their actions, they are able to criticize them and to focus on the preconditions of patients' autonomy.

Besides, it seems that nurses are able to list the preconditions of all autonomy dimensions but do not acknowledge that a considerable part of autonomy depends more on nurses' skills than on patients' skills. Moreover, it seems that when one of the dimensions is limited (e.g. lack of communication skills or physical impairment) autonomy is absent, i.e. the part is considered as the whole.



#### **4.1.3. What is empowerment?**

In the first approach to data, it could be stated that nurses do not know what empowerment is. “Empowerment is a new concept... I heard it here for the first time...” (N7; OR) “I never thought about the concept of empowerment...” (N6; DN) In fact, many nurses declared that they did not know the meaning of the concept, had never heard the word before, and those who had, had never reflected on or discussed it. However, during the seminar, the idea of empowerment was explored to highlight the idea, in order to allow discussion. Nonetheless, in the first material produced by nurses (oral recitals), the word empowerment is only used by three nurses (N7, N10 and N11) and just eight times in the overall narratives. N7 firstly says “I don’t know what empowerment is” and subsequently she states that it is possibly the nursing action towards chronic patients in order to give the information related to lifestyles:

I think that empowerment is related to chronic patients (...) to the need to teach patients... we try to give them the information ... all the information to entitle them to choose what they want to do... teach about nutrition, about lifestyles. (N7; OR)

Nurses 10 and 11 always use the combination “autonomy and empowerment” suggesting that they do not recognise a clear difference between the concepts. Moreover, what they really describe are disempowering situations. To N11, the idea is related to following rules:

My grandmother... I think she quite lost her autonomy and empowerment when she had to move from her house and started living one month with each daughter. (...) Even if she had her own room in their houses, she had to follow family rules. (N11; OR)

Thus, it seems that moving from one’s house and starting living one’s daughters’ houses leads to disempowerment, as it is necessary to abide by other people’s rules. Nurse 10 uses five times the binomial “autonomy and empowerment”, in four different situations:

My grandmother was a very active woman but when she became impaired and frail...due to a stroke... maybe she should have had more autonomy and empowerment to make her decisions. Her requests were limited and it turned her

less dynamic... her dynamics was suddenly truncated. This taught me that impaired people should have the opportunity to be actively involved. (N10; OR)

In this situation, an external event (disease) modified individual freedom. However, in this narrative, nothing points out any cognitive impairment, physical consequences only are mentioned. But it seems that, owing to this, the family assumed a paternalistic attitude.

My mother-in-law was also very active... she was 85 years old (...) and she had some auditory deficit (...) but she wanted to be in her house, and she managed to do it (...) One day the social workers visited her and decided that she should go into an institution because she was at risk living alone. She didn't want to go... she accepted against her will. She used to say "they bath me... they do everything... I'm not allowed to do anything." In three months she became impaired, frail, lean, she lost strength and vitality. Suddenly she was ill and died... This situation showed me that it was wrong to completely take away someone's autonomy and empowerment. (N10; OR)

In the excerpt above, again, an external cause is the reason for a sudden change. The Social Services decided that someone is unable to continue living alone owing to hearing problems and the individual's decision-making power seem to have been completely ignored. This is a disempowering situation, leading to illness and death. In both cases, at the moment that the events happened, family members were not aware of the possible consequences, as the aim was to have a beneficent attitude. However, through reflexion, this nurse is acknowledging that good intentions might have poor outcomes, if an individual's will is ignored and if disempowerment occurs.

As far as professional situations are concerned only brief references appear:

I think that the use of restraints reduces patients' autonomy and empowerment (...) Physical freedom is important to patient empowerment and dignity. The use of restraints is shocking. Sometimes, we are obliged to use restraints and I think that it leads to indignity and disempowerment. (N10; OR)

The citation above is clearly related to physical freedom and to dignity: it seems that to this nurse the use of restraints is the ultimate evidence of complete disempowerment. Hence, to increase an individuals' freedom of movement is a way of promoting empowerment:

And when I had a patient that used a stroller at home and I asked the family to bring it from home... I think that I did contribute to her autonomy and empowerment. (N10; OR)

With reference to the previous citations, it is interesting to note that while two of them report nurses' family situations, the other two report professional circumstances. In addition, while family related events include narrative excerpts, statements related to professional situations are quite brief and cautious, using the expression "I think that". Moreover, while family situations are related to decision-making, professional situations are related to physical freedom. In other words, it may be stated that, in their professional context, nurses believe that physical freedom interferes with patient empowerment, by being related to one autonomy dimension: to be able to do. However, with family members, the issue is not to be able to do but to be able to decide what to do. Thus the issue is to give the freedom to do and the freedom to decide what to do. Furthermore, it should be stated that there are significant differences between the individual's potential to live her or his own life and to make independent decisions and the third parties' (staff or family) assessment. In other words, staff and family have lower expectations regarding older people's autonomy and decision-making power and underestimate their remaining skills.

These are quite brief testimonies, involving directly and explicitly the word "empowerment". In fact, it seems that the strongest message is that the word empowerment is largely absent from nurses' oral recitals, that the concept itself is quite unknown and that the few existing excerpts are related to disempowering situations. Thus, I looked to written data, trying to find some more information about it, or some reflexion, namely in the diaries, and new information started to emerge:

I think that somehow it is easier not to think and not to question one's behaviours as health professionals and as persons. I never thought about empowerment. I never realized how I was disrespecting older people. (...) I felt a little frightened. It is absolutely vital to give older people the power they need, which usually doesn't happen. I also did it myself: I took decisions on patients' behalf without being asked to. (N16; DN)

Hence, perhaps that besides not knowing what empowerment is, nurses feel that this is a very uncomfortable issue. This testimony is quite clear and sharp: to reflect critically about power in nursing care is hard and disturbing. It is easier not to think about it. To reflect upon empowerment is to bring some less respectful actions under the spotlight. She also clearly states that empowering care usually does not happen, as nurses assume they know what the best choice is for their patients. Nevertheless, there is also the acknowledgement that empowerment is absolutely vital:

Besides other things, empowerment is important to allow patients to have an active participation in building their own lives. This will lead to increased motivation, self-esteem, self-confidence and freedom to act. (N10; DN)

Thus, when nurses stop to think about what empowerment is and why it is a relevant issue, they also start to identify some dimensions of empowerment: patients' freedom to decide and to act, as well as the right to participate in decisions and in care. However, through a return to the data it is possible to identify in the nurses' testimonies many influencing factors which may be considered the real cornerstones of empowerment.

#### ***4.1.4. Cornerstones of empowerment***

Even though nurses do not use the word empowerment often they are able to describe related events leading to empowerment cornerstones, either relying on nurses' attitudes and behaviours or depending on patients' profiles.

##### **Nurses need critical thinking**

For empowerment to occur, nurses need to develop critical thinking skills. In addition, they should stop making decisions on patients' behalf without being asked to do so:

I learned that most part of the time we do not stop to think, to reflect on what we are doing (...) particularly with older people there is always someone that

assumes decisions on their behalf, either if they have on their full mental skills or not. (N16; DN)

It is acknowledged that often nurses assume themselves to be the natural decision-makers because they do not stop to question their own behaviours.

When I listened to our teacher's narrative I suddenly became aware how wrongly I took autonomy and empowerment in older people. I realized how many times I forgot that older people are free to make their own decisions (...) and that I need to enable people to be self-directed, to preserve their rights as citizens and to give them the freedom to choose. (N11; DN)

During the Biographic Approach Seminar, nurses had the time to think about nursing care: they analysed actions, behaviours and events and they "suddenly became aware" (N11; DN) that there is a lot to do regarding patients empowerment; namely, by preserving patients' citizenship rights. And one of the patient's empowerment cornerstones seems to be nurses' lack of critical thinking:

The lack of reflexive attitudes from nurses leads to lack of autonomy and empowerment in hospital (...)When we listen, we feel the other's feelings, his needs, his fears and concerns... and sometimes, overwhelmed by our work we pass by... aside from people's histories. (N1; DN)

Hence, when nurses reflect on practice they are able to identify what patients really need and many testimonies recognize this need for critical thinking. However, reflexion seems to be apart from everyday practice and some reasons may be found in nurses' testimonies. Firstly, it may be frightening, as Nurse 16 said before: it is not comfortable to conduct self-assessment, and to realize one's frailties. As she says, "I never realized how I was disrespecting older people. (...) I felt a little frightened." (N16; DN) In addition, nurses are overwhelmed by work and "pass by... aside from people's histories" (N1; DN). Workload may be an important obstacle to critical thinking; nevertheless, in the context of the rest of the narrative, it seems that being overwhelmed by work may also be interpreted as being overwhelmed by a work routine: "as it looks that it is automatic... mechanical..." (N1; OR).

When we are young nurses we do not stop to think about things... For example... the patient stops [cardiac arrest] ... we do CPR and we move on... we do not think about the action in itself... but after a while... I think that we start

thinking over it... For example I had a patient she had a heart problem... she was really dying... and they [physicians] even performed an angiography... and she should stay still in a supine position... but she was not comfortable... she wanted to be turned laterally...she was already taking morphine... but she couldn't sleep... she wanted to move a little... what difference would one more haematoma make? If I turned her to lateral decubitus the back pain would be relieved...And I told him [the physician] ... I deeply regret that at that moment I turned my back and left... to avoid interfering with his work... On the other day I knew that she was dead... but they even put a pace-maker. I may understand their point of view but it was unnecessary pain. (N9; OR)

In this precious example two different reasons are presented: in the first place, automatic behaviour is illustrated: “we do not stop to think about things... For example... the patient stops ... we do CPR and we move on”. Moreover, it looks as if there is nothing to think about following a cardiac arrest, as the standard is to perform CPR. Nonetheless this sentence is inside a wider context where the point is not CPR after cardiac arrest but biomedical routine against a patient's will. In other words, an end of life situation is described when to follow a protocol (patient must be in a supine position after an angiography) prevailed over a patient's need for pain relief. The focus is on a clinical condition and not on the person. But it is also a matter of the physicians' power over nurses' power: “If I turned her to lateral decubitus the back pain would be relieved...and I told him (the doctor)...” Hence, the nurse was able to focus on the patient's needs and to say so, but apparently the physician did not agree, as she says: “I deeply regret that at that moment I turned my back and left... to avoid interfering with his work...” Though this nurse did have critical thinking, she says that she turned her back to avoid interfering with the physician's work. Furthermore, one word at the beginning of this excerpt could be considered very significant: the word “young” in the sentence “When we are young nurses”. It is not explicit if “young” is age-related or experience-related but it is possible to read between the lines that some inexperience might be present and that nurses also need empowerment (i.e. when we are young we must follow rules and we do not have power to contest routines or physicians' power). Thus, it is possible that patients' empowerment also requires nurses' empowerment.

In summary, it seems that in order to promote patients' empowerment nurses need:

- To be aware of the meaning of empowerment and its relevancy in the context of care for older people;
- To be aware that often they assume decision-making on the patient's behalf, without being asked to;
- To develop critical thinking skills and to have opportunities to do so in order to be aware of their own attitudes as well as patients' needs;
- To feel empowered to question decisions or behaviours that are opposite to the patient's will;

### **Patient profile**

The patients' profile regarding empowerment issues seems to be divided between two opposite characters: the "good patient" and the "stubborn patient". The good patient is the one who "does what we say at the moment that we want." (N6; IV) This passive, or even submissive, behaviour is welcomed by nurses as it is easier to care for patients who just follow nurses' prescriptions:

They have good will and they say "I'll do everything to help you." (...) people with more passive behaviour are good to nurses but it is also good for them (...) and some patients do not even need to make a big effort.' (N6; IV)

Moreover, the good patient "is patient [has patience], does not complain, does not get angry" (N14\_WR), i.e. she or he keeps control of her or his own feelings. Additionally this nurse believes that to be submissive is good for patients, as well as for nurses. Further, patients are often induced to accept clinical decisions. As stated by one of the nurses:

Sometimes the patient does not want to undergo surgery... and I think we should accept it without trying to persuade them another way... but that's what we often do... we try to convince them, to persuade... that it is a better solution... I don't

know... sometimes we say that they are not in their own mind... and at the end the patient accepts (...) I don't know... but I think that sometimes we manipulate older patients... (N9; IV)

This excerpt is quite strong: the verbs used to describe nurses' actions are to "persuade", to "convince" and to "manipulate", all of them mirroring disempowerment attitudes. Moreover, this nurse acknowledges that it is a wrong attitude, but that nonetheless nurses exhibit it. Once again, the focus is on disease and not on the person being treated. However, in the nurses' narratives it is possible to find patients that accept clinical decisions and patients who refuse them:

Mrs Sofia was an 86 year old lady with the diagnosis of breast cancer. (...) After a biopsy and very much aware of the results she refused surgery, immediately and without any doubt, without asking nobody's advice, stating with the conviction of someone who knows exactly what she wants: "No way, Doctor! I'm not going to finish my days without my breast!" And despite the physicians' persistence, and all the information given, she was firm in her decision until the end. (...) She had the strength, as well as family support, to keep her decisions. When she went to hospital, at 92 years old, she lasted 2 days... (...) I'm not sure if she would live until 92 if she would have lived until 92 if she had been coerced to do otherwise. (N20; WR)

In this testimony, a few things capture the attention. In the first place, the decision is taken when Mrs. Sofia is an outpatient, immediately after diagnosis. In the second place, information was given but the patient revealed persistency in her will, and she had family support to maintain her stance. Finally, it is a decision related to treatment options and not to nursing care. This nurse considered it a wise decision as the patient lived for 6 years and only went to hospital for her last two days: "I'm not sure if she would have lived until 92 if she was been coerced to do otherwise." Again, the verb "to coerce" appears without any criticism.

I met a patient who in spite of some physical impairment had full cognitive skills. He never stopped making his own decisions, evidencing great autonomy and self-determination. He's 78 and he was hospitalized due to an acute respiratory crisis. He uses oxygen at home. And while he was in the hospital he developed strangulation of an abdominal hernia (...) and the only possible treatment was surgery but with major risks due to his respiratory condition; however, he decided that he wanted to have surgery. His wife and daughter were very worried and



tried to persuade him to quit surgery. But as he used to say “I’m very stubborn.” And he had surgery even against his family’s will and it was successful. (N19; WR)

This excerpt has some similarities with and differences from the previous one: both were cognitively well and assumed a decision related to surgical treatment (not related to nursing care). Both had information and were aware of risks. But the contrasts are evident: he decided against his family’s judgement: they tried to persuade him not to do it and the decision was to have surgery. Again, this nurse reports it as a wise decision as the patient survived. Both descriptions reveal some admiration regarding patient’s inner strength to keep to a decision, independently of family or clinical prognosis. However, these situations are not related to nursing care and it would be relevant to find out what happens when a patient reveals this strong will, or inner strength, regarding nursing care:

I remember a significant experience of a man with a tracheotomy, he was nearly 70 years old...He was an obstinate men... and his will always prevailed... it was interesting because he couldn’t speak ... but he stamped his foot... to make us see that it was the time to care for him, to clean the tracheotomy, or whatsoever... I... I must admit that I do not like that someone tells me what I have to do... he was really determined... But it was quite funny... because... in spite of having a significant communication obstacle... in spite of limitation... he succeeded to keep his will... his will really prevail. (...) He was persistent... a strong will... not lying down in bed to quit... or to die... he wouldn’t let life pass by without deciding whatever he could... whatever would be in his hand. (N6; OR)

This example is quite interesting. The nurse feels uncomfortable as she does not like being told what to do: she uses the word “obstinate”<sup>10</sup> and says that the patient “stamped his foot”<sup>11</sup>, which means that the patient imposed his will. But, subsequently, the discourse changes (“it was quite funny”) she accepted the patient’s requests and, at the end, it suggests admiration: “He was persistent... a strong will... not lying down in bed to quit... or to die...” It is also important to

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<sup>10</sup> In Portuguese, this has a negative connotation.

<sup>11</sup> In Portuguese, this is used to describe a stubborn and rude child. In this context, it is used in a figurative way.

underline that this patient had a communication handicap: “he couldn’t speak”. This was also a surprise as nurses considered that autonomy depends on verbal communication skills. However, in spite of the non-existence of oral communication, this patient was able to enforce his will through his body language, because of his character: he is “obstinate, (...) determinate, (...) persistent”. As in the two previous examples, the patient has the persistency or the inner strength to make a decision, to communicate it and to stand up to family, nurses or physicians. And it seems that is not enough to have the right to be respected either in a legal or ethical perspective. Sometimes patients must be themselves to claim this right:

The first memory I recorded... It was once in the hospital someone of the staff asked an old lady “Hi granny, what do you want for breakfast?” And she replied: “I’m granny of my grandchildren” (...) I remember that image... I never dared to call anyone “granny” (...) it remained in my memory... It’s almost like disrespecting the person... saying “granny” to a stranger. (N13; OR)

Besides being an example of a paternalistic and disrespectful attitude, the point is the patient’s attitude: she contests this kind of approach and teaches a lesson that remains in the nurses’ memory. Moreover, in previous examples, patients are claiming out loud their right to be listened to and respected. Thus, it seems that nurses are saying that patients’ personality is important as far as empowerment is concerned, i.e. the submissive will be submissive and the strong and empowered will keep empowerment.

But, beyond the patient’s character, other reasons influencing empowerment in hospital may be found:

I think that it may be related to family environment, isn’t it? I do not know from what kind of environment people came from... and sometimes they are already used to being submissive... a kind of... well... not having lots of freedom... perhaps they no longer live in their own home... perhaps they do not have their money to manage anymore... I don’t know... Sometimes old people who live alone are more supported by family than those who live with the family and are ignored and rejected... (N9; IV)

This example raises a new argument: perhaps patients are already powerless when they are admitted in hospital. They are used to being ignored in decision-making for social and family reasons. And this argument makes good sense, as nurses' narratives are full of examples of older people who, owing to some physical impairment, had to move either to a nursing home or to their children's home. Thus, they are already abiding by institutional or family rules. The following excerpt is an example of this:

I met a couple, they were always together. He had a prostatic cancer and she a gastric cancer. He cared for her and she cared for him. (...) He had a mind of his own. (...) When she became a terminal patient he succeeded to keep her in their environment (...) their sons were there and respected their will. (...) After she passed away the sons started to feel tired (...) and took him to a nursing home (...) against his will. (...) He became a sad man. When he was in hospital he used to talk with us (nurses) but after that he became quiet, his head hidden between his shoulders. (N1; OR)

Thus, besides the discussion whether the family exists or not, if the family comes to hospital or not, is the question whether the family is willing to respect older people's decisions. In the previous example, this is quite clear. As a couple, these older patients managed to keep autonomy, contributing to each one's empowerment. But, when one is alone, the children assume control, disempowering the widowed. However, sometimes patients relinquish power by transferring their decision-making responsibility to the family:

Most part of them pass this autonomy to the family, to someone significant to delegate that stuff... they usually say: "Well, this is to my daughter, talk to my daughter" and so it happens now with elderly patients... we deal really with the family. (N7; OR)

Thus, in nurses' narratives there are patients that are able to keep their will independently of having a family or not, there are patients who relinquish power in favour of a family member, and there are also patients that need family to support them and help them to be listened to and respected.

### **The focus on patients**

One of the reasons nurses pointed to for empowerment to happen was patients' personality or behaviour, as some patients are able to grab nurses' attention through their acts or their personality. Nurses describe them as strong characters or persistent people. But there are other circumstances that may attract nurses' attention and lead them to focus their attention on patient centred care: "I had a patient 100 years old... very sweet. The skin was completely wrinkled, quite pale, deep eyes... he was totally dependent on care." (N10; OR) In the first place it looks as if a frail look may also awake protective feelings in nurses towards older people, particularly if they look vulnerable and are nice at the same time. But another particularity was attention-grabbing:

When we look at Mr. António we feel immediately the need to protect him because he looks frail, slightly bent, short stature, gray hair, spectacles and auditive prosthesis, the typical image of grandfather... and he even wears a hat. He has always shown a large autonomy and a huge spirit of sacrifice towards his own family (N18; WR)

Hence, these images of sweet, tender and frail old bodies seem to arouse nurses' emotions, as they look like real grandparents: "They need someone to touch them, to give them attention... someone who gives them a bit of attention, someone that gives them some affection". (N9; OR)

In this testimony, nurses are identifying themselves as possible substitutes for a family who does not exist or does not care. Loneliness is fought by nurses through attention, affection and human touch. The following excerpt is very suggestive of this identification with a family role:

I had an 88 year old patient, his son was a physician... he was a very demanding and stubborn patient... he wanted to do things by himself... to go to the toilet, to dress, to bath... he always participated in care... but after two or three months things were not going well... in his face a mix of sadness and grief... and he started to refuse to eat, to bath... he started to say "No!" with a rough voice... And he stopped taking care of himself... we started to take him in a wheelchair to the shower... and if we asked him about what he would like to eat he remained silent... We asked him what was happening but he remained silent... but one day he started to talk to me: "I'm abandoned, I'm here alone... nobody comes to see

me” and I replied: “How is that so? We are here with you.” But he stated: “This is not about you... you are kind and good to me... I’m sorry if sometimes I’m aggressive and tell you off... it is not about you... it’s my family... they do not even come to see me.” He spent almost one year in the ward. We used to play with him, to tell him jokes... he missed his children’s love... and somehow we replaced them (...) He found in us the love not given by his sons... and we tried to reply. His autonomy was lived through care refusal... when he told us off... when he was angry... His empowerment was having this freedom with us. (N10; OR)

In this testimony, the “demanding and stubborn” patient participated in care and did things by himself. But he missed his family affection: as the nurse says, his son was a physician in the same hospital and he almost never visited his father. It seems that this family does not care, which leads to the patient’s depressive mood: he refuses care and refuses to participate. Realizing that the patient felt somehow abandoned, nurses tried to replace his family. As in other testimonies, this nurse tries to be the family the patient does not have. And, to the extent the nurse was able to focus on the patient’s situation, she was able to understand and accept that his remaining power was lived through care refusal and through the freedom to express his feelings.

Thus, it seems that it is possible to welcome other manifestations of autonomy, besides physical dimensions of self-care and that to refuse care is also a right. Moreover, she realized that this man needed the human dimension of care. When she says that nurses tried to give back patient’s unrequited love, what really happened was that nurses stopped just looking at tasks and started to look at the patient, tried to understand him and to care for a person in the singularity of his concerns. Nurses were able to know the patient and to respect his will. Nurses acknowledged that “To care for someone requires knowing him in order to be able to identify his needs.” (N2; DN)

Hence, one of the conditions for the empowerment of patients seems to be to know them, knowing the person and identifying her or his needs. This requires gathering information about that person’s life, routines and wishes:

I had a patient 100 years old (...) he was totally dependent on care. We didn't talk... he only whispered a few incomprehensible words. (...) He had a nasogastric tube to feed him. But his family informed us that he would be able to eat if we used a baby' bottle and gave him soup or liquid... And we asked them to bring it... and he really ate well. He always followed us with his eyes and sometimes outlined a smile and once in a while he grabbed our hands... like he was thanking us. (...) I learned that this is empowerment too. And I also learned that if the patient is not able to communicate we are the ones responsible for his quality of life, even if he's cognitively impaired he has the right to be cared for with dignity... (N10; OR)

This nurse describes the relevancy of knowing patients' habits: if the patient is not able to speak it is necessary to look for someone who might know her or him, namely the family. The outcomes here were positive: improving patient freedom of movements, improving comfort, reducing unnecessary tubing and, moreover, an evident improvement in patient's well-being and satisfaction: "he always followed us with his eyes and sometimes outlined a smile and once in a while he grabbed our hands... like he was thanking us." Then nurse concludes: "I learned that this is empowerment too".

Helping patients to gain some control over their situation is also something brought by nurses into their narratives:

I remember an old man... he had cancer... he was partially dependent and I used to give him his belongings and the washbasin and all stuff and gave him time to do it alone... just helped in his back and ... to finish. At the end he always thanked. (...)One day he called me and showed me a little booklet: "This is my diary, all important things are here" And my name was in it. (N10; OR)

In this example, there is an active intervention towards patient empowerment: instead of quickly performing the task, the nurse gives the patient the tools and the time to do it. Apparently, the nurse just realized how important this intervention was when the patient told her. But, in spite of this event having happened in an acute care ward, it is a palliative care situation. However, the examples found of patient empowerment were all end of life situations:

I had a patient, he was a frequent patient in my floor (...) he was in an advanced stage of disease and we realized that he was dying (...) he had oxygen, and the tube fell out...and I said: "I must replace it in your nose!" And when I put it in, he took it away. And I was going to replace it again and then I thought: "No! I'm

not going to do it... if he doesn't want it I think he has the right to ..." (...) He died 2 days later... and I think that often we abuse a little of the "you have to...", "I must do" or "It has to be..." and we often do not think of patients' wishes. (N13; OR)

In this situation, the nurse was able to read the patient's information: she understood that the patient did not want the oxygen and changed her attitude from "I have to do this task" to "the patient has the right to". She was able to change the focus on the illness to the focus on the patient. But, again, this was an end of life situation. Thus, I looked to at data and tried to find other situations that might be acute care and not palliative care:

I had a patient... she was very anxious... regarding hospitalization... and very gassy (...) she called us daughters... and she always wanted to be in right decubitus, as she only felt comfortable like that (...) but we feared bed sores and didn't let her turn into the right position. Only when we started discussing these issues in class did I realize we could have listened to her... we forgot her feelings, her decisions... we were too severe in our decisions as nurses. (N11; OR)

In this situation, the nurses' will prevailed. Independently of a discussion around pressure ulcers risk, the point is that this nurse acknowledged that she had difficulties in listening to a patient's feelings, or even to negotiate a solution: nurses just decided. Thus, there is a critical view of care, much later, but the action itself was focused on the pathology, not on the patient as a whole. These three above examples thus confirmed the interpretation that to empower patients and promote their autonomy nurses need to move from a biomedical paradigm, focused on tasks, on healing, on medical procedures, towards a humanistic approach focused on patients' needs. Moreover, it seems that in end of life situations this is easier to achieve than in other situations when a patient's death is not imminent.

To summarize the nurses' point of view in patients' profiles, several topics have emerged. Firstly, patients are described vis-à-vis their submissive or assertive (even stubborn) behaviour. Good patients are identified in the submissive pattern, the ones who follow rules and routines and who accept clinical decisions. Nevertheless, nurses admire patients who are able to make their will prevail over

family, physicians or nurses, as long as the outcome has been a longer life time or clinical success. Furthermore, nurses acknowledge that some patients are able to influence nursing care through a more proactive attitude, which is related to personality traits. However, passive behaviour is encouraged as it makes accomplishment of tasks easier. Nurses' action is largely described as being focused on tasks, routines and clinical procedures, to the detriment of being patient-centred, which latter requires knowing the patient and her or his routines. However, some extreme situations of age (e.g. patients' over 100 years old), frailty, abandonment or end of life often guide nurses to patient-centred care. Finally, nurses consider that patients' relationship towards family (if existing) may influence empowerment.

#### ***4.1.5. Looking to the wider context: hospital, family and society***

In nurses' childhood memories, hospital seems to be a place to avoid as loved ones go there and do not return: thus it is a place of death. Later on (in nurses' professional experience), hospital becomes the place where family drop off their older relatives, a cold and dehumanized place where older people wait a long time for care. In hospital, physicians are focused on diseases and have strong power and nurses are more concerned about tasks than about people. Moreover, hospital is described as health professionals' territory, with implicit rules and routines that patients must follow.

#### **Rules and routines**

Nurses often bring the issue of rules and routines as possible causes of patients' disempowerment: "Autonomy is a value often forgotten by nurses, somehow due to many inflexible rules" (N1; DN). Hence, I looked to the data in order to explore what nurses consider as inflexible rules and who sets those rules.

I had several patients that we... well we set the rules: time to get out of bed, time to bath... I think that older patients do not accept to take a bath every day as we



impose on them... And it happens that we take patients to the bathroom and they do not want to shower. I did it many times... imposing the bath when they didn't want. (...) At home they do not have a bath daily... it is once or twice a week... but here is the rule and I did impose it many times... (N3; OR)

In this excerpt, the rule is quite clear: the patient in hospital must bath every day. And it seems that nurses assume the obligation to ensure that patients will follow it. Moreover, the verb used is “to impose”. This nurse clearly states that she did impose this rule quite often against patients’ will and usual practice. She knows that at home it is different but in hospital there is a rule. However, she also acknowledges that nurses set the rules: “we set the rules: time to get out of bed, time to bath...” However, this is not an explicit rule; in fact this is a routine. Nobody knows who started it, most people do not agree, but everybody does it. And besides bath or shower there are other rules:

Something that always upset me was... when patients are admitted to hospital... particularly older patients... to take all the clothes off. I remember old ladies that used to say: “Well, I must be deprived of my clothes? I never ever showed my naked body... not even to my husband, and I’m going to take all my clothes off?” Older people do not accept it. (N13; OR)

The rule here is: a patient in hospital should not have personal belongings, namely clothes. Once more, this is not a written rule: it is a routine. Removing patients’ clothes and belongings is not well accepted by patients, particularly older people, also because of physical exposure and bashfulness. Once again the nurse feels upset however she complies with the “rule”. But there are places where it seems that it is different:

Something amazing I had the chance to see was in palliative care (...) there is no routine: not for bathing, not for feeding, not for medication... (...) the patient decides when he wants to bath, to eat... (...) it is not like in our hospital units that at 6 o’clock in the morning it’s Hei! Let’s go to shower! Hei! Come on! Let’s use thermometers! Hei! Hurry up: Let’s check vital signs... And often this is disruptive to patients. (N1; OR)

This example evidences patient empowerment in a palliative care unit: the patient decides if she or he wants to take a bath and when or when she or he wants to eat. Thus, when care focuses on patient well-being, there is no routine but an

individualized care plan. But this testimony reveals that this is an exception, “something amazing”, the opposite image of “our hospital units”.

Hence, nurses acknowledge that some rules often do not make sense; some of them are just routines and may be disruptive to patients. Also, in one of the interviews, the issue was brought up and the following excerpt is quite revealing:

Well, in institutions there are rules and rules... There are rules that we like to follow, when I say “we” I mean health professionals who work there, and there are other rules that... well... we like to follow the rules of giving the bath and make beds, in order to have all things done, to get on with all the work (...) but institutional rules are difficult to be broken... (...) but rules, rules are made by people who work in hospital... isn't it? As rules are not so rigid like that... People who work there must make the rules... As rules are in people's mind, they are not written... in so many years that I work there and I never saw these kind of rules written anywhere. The rule is a tradition, people are used to do in a certain way and when someone joins the team does the same way, as others do... and it's a cycle (...) but I think that it's in nurses' hands to change things(...) but to change routines upsets people (...) we like to organize tasks. (N6; IV)

This nurse points out many contradictions regarding the alleged rules. Firstly, the institutional rules are just in people's minds. They are not written anywhere and, in fact, they are traditions or routines. Besides, routines are in staff hands and nurses may change them if they want to. However, it is comfortable to keep routines as they are task-oriented and nurses want to have things done but also because to change rules upsets the team. Many of these routines are explicitly mentioned: patients must have a bath early in the morning, nurses decide when to eat, what the patient wears, when it is time to sleep and time to wake up. Nurses decide visiting hours and expect the patient to be next to her or his bed. Thus, it seems that nurses have enough power to set rules but do not have (or do not want to have) enough power to change them, even if these rules are disempowering patients and do not make any sense.

### **Family and society**

The family is thoroughly described in nurses' narratives not only at the time of hospitalization, but as part of a wider scenario that mirrors social changes. In their

childhood memories, nurses describe families living in rural areas and being large families. Usually, three generations lived in the same house and, nearby, there were other family members, neighbours and friends. People worked in agriculture and it was possible to coordinate work on the farm and care for ill or dependent people.

They were independent. Lived for eighty years on their land, worked in agriculture, had animals... the land was their life. (...) but then they got dependent and ill and we lived in town, faraway... (...) Now there aren't several generations in the same house anymore or 7 or 8 children there to help... (N3; OR)

In the present days, reality has changed. Children have moved into urban areas and have jobs and obligations that make them be away from home for long periods. Only one or two generations live under the same roof and to care for someone with physical limitations has become difficult. The immediate consequence is that older people no longer have a large family in the house or nearby. They must leave their home environment and move to the town where their children live, yet the children are unable to provide care:

We brought my grandfather to Setúbal to have surgery... (...) but they wanted to return... land was their life. They stayed with us for recovery. I wanted to provide them all the care they needed. But my father had his job, my mother had a cardiac problem (...) and I couldn't stop working to care for him... (...) The only solution was a nursing home (N3; OR)

The solution is a nursing home or constantly moving from one house to the other, splitting time between sons and daughters, one month in each house, losing power over their environment, as they are the guests who abide by the hosts' rules.

When Mrs. Jesus became unable to cook meals, and to do the housekeeping tasks, she started to go to their children's house, moving from house to house, from place to place... it was a sacrifice to her... she never liked to be in their children's house. (...) She became a sad person, always sad because she was not at her place, at her house... Then she got more and more dependent and their children considered the possibility to send her to a nursing home, but she didn't want... she never accepted it... but sometime after they decided to put her in a nursing home... The sadness was so intense that after one month she had a stroke and gave up, she quitted living... and she died. (N1; OR)

Thus, it looks as if the family is not as it used to be. Following social changes, older people no longer live in the same environment with other generations under the same roof or nearby. Children's work schedules hardly allow them to provide home care for sick and dependent parents. Additionally, there is a lack of social support provided at home by public services. Thus the point may be "that family is not able to provide care" and not "that family is not willing to do it". Furthermore, this situation may lead to patients' disempowerment.

It would have been possible to continue working on the nurses' narratives as this material was so rich and extensive. And it seemed that each time that I went back again to these nurses' narratives new data arose, making interpretation an endless task. Nonetheless, I believe that the most important issues have been presented and that it is vital to move now to the patients' point of view.

## **4.2. Exploring the patients' point of view**

Through the exploration of patients' testimonies some core themes emerged: the meaning of the concepts involved (autonomy, dependency and empowerment) over the lifespan, the meaning of the experience of ageing and its influence on autonomy and empowerment and the meaning of the experience of hospitalization.

### ***4.2.1. The meaning of autonomy***

When older patients were asked to report events related to autonomy over the lifespan many issues were brought up, either related to them or depending on the environment. However, in first place, "Autonomy is to do whatever we want" (P4), "autonomy is to be able to propose and dispose... to my will, to be independent... independent from others..." (P3). Self-determination is one of the issues most referred to, encompassing freedom of decision and of action, the necessary skills

to do it, managing one's life without needing to give further explanations to others.

I never owned myself... ever... As you see... I was 12 when I left school; I was admitted at 5 years of age, to a day-school... my father had died, my mother was a market-vendor and while we had money the school was paid... then the money ran out... At 12 years old I had to start working with my mother... so... I never owned myself, like now, I never did, I had my mother always around, isn't it? Then in my life... well, I married at 18, had my first daughter at 19... I suffered a little with my husband... for 34 years... I had 8 children...it was hard... (...) Yes, well, I was widowed 16 years ago, I never married again, I didn't want to... It was hard to live with the first one... no way... And now my children are adults, some ones keep single, others married and others divorced... that's it... that's my life... (...) But now I only depend on me... I own myself... I do what I want, I think what I want, if I want to say anything to my daughters I do, what is right or wrong, well... I say it... if they want they accept, if not it's their problem... but now I'm independent (...) I make my own decisions, my way, it's my house and they are not against... (P1)

Patient 1 describes two different periods of her life; namely, before and after becoming a widow, before and after being the owner of her life. Firstly, when she was a child, she had no voice and no choice: she left school owing to financial problems and abided by her mother's rules. Then she married, she was not a happy person and continued to be owned by her husband. Subsequently, she was widowed and she had the possibility to choose: and she chose to be the owner of her own life, i.e. she has the freedom to think, to speak, to decide and to act. Furthermore, as she says, she is in her own house, thus she makes the rules. And to live in one's house seems to be an important issue as, besides the freedom to set one's rules, it allows the person to have freedom of movement, e.g. freedom to choose one's social life or freedom to change job:

My dear, to be autonomous to me is... I live alone, I have my house, my friends, my family, whom I adore... we socialize... I visit ones and others... I stay for a while in ones' home... I stay for a while in another's home... then when I want I go home... I do what I like to do... I go and I return when I wish... I do not have

to explain myself to anyone<sup>12</sup>. (P2) In my life I always did what I wanted to, even things that others didn't want I used to say "yo...ok...fine" and then I did what I wanted to. (P2)

Autonomy? In my life... is to make decisions...one day I worked in one place and on the other day I decided to go elsewhere and I did...(...) I think that all my life I owned myself. (P5)

Thus, older patients describe themselves as autonomous people as "Autonomy is to determine our issues... to make up one's mind... to sort out our own life... In my life I always did it." (P12)

In all previous examples, it is clear that freedom to make decisions and to take actions according to one's mind and will, independently of other persons, is at the centre of autonomy. Autonomy is related to self-determination and outside any kind of submission. Actually the need to be submissive is identified in different situations as a limit to one's autonomy:

Well, how shall I say?... it is like... the person is old enough to discern ideas... to distinguish his thought from the others (...) but there are occasions... when we are not entitled to do what we feel, because the law doesn't allow it, or the boss does not allow it... [Interviewer: The law? Could you explain it?] Maybe when I attained majority... maybe that... I grew up, I attained majority and I was entitled to dispose ... to do my will... as I wanted. Up to that moment the family controlled more. (...)After that age I started to sort out my own issues without needing anyone (...) Yes when I attained majority I started to be the boss of myself... but since I was an employee and I had a boss I had to obey. It was according to the boss's orders... (P15)

To this patient, two circumstances impose that kind of submission: the law and the boss i.e. to be under 18 years old (the legal majority in Portugal) and to be under a working hierarchy. In both situations, it is necessary to abide by other people's rules. One of the patients clearly states:

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<sup>12</sup> The expression used in Portuguese is "*dar satisfações*" that may be interpreted as giving explanations related to one's actions, almost as a justification to someone hierarchically superior who may have the power to give permission (or not) for these actions.

I always taught my son that I didn't want to work for others, to have bosses, only if we do not have another solution... to abide by other people's orders... only if it is impossible otherwise. Always tried not being under others' orders... (P4)

To be an independent worker means not having to obey other people's rules. However, it is also necessary to be over 18 years old to be legally entitled to rule one's life: "When I was 19 I started to rule my life... I bought my working tools and started to work. I was a good worker and everybody wanted my services..." (P14). It seems that older people identify as important to autonomy to abide by one's rules i.e. ruling one's own individual and professional life and not needing to submit to family rules or bosses' rules.

Hence, self-determination and self-government are important issues in achieving autonomy. However, a wider meaning of autonomy related to other individual issues, namely, self-awareness, self-development and daily life management, is reported:

Well, I think that autonomy is what we've been through, isn't it? Is what we've done, isn't it? And it is what we are going to live ahead, from now on... Yeh...right! I declare that autonomy is knowing what we are, knowing what we do, and knowing what we are going to do ahead! (P1)

Autonomy is much more than just making decisions: it's being able to keep congruency over time, having self-awareness, knowing "who we are and what we do". More than just making casual decisions, autonomy is a continuous and meaningful lifelong process over past, present and future. It also seems to be important to have projects ("knowing what we are going to do") and to be able to adapt to changes:

Life has changed, but while I'm aware I'll rule my world (...) some things changed... now we have computers... I do not use it because I do not need it but there are other changes... life changed a lot... how shall I say... the coin, for example, the professions... now we have the Euro... now a woman goes to the army... when I was young, a girl would never meet a boy alone... we married... now my younger grand-daughter lives with her boyfriend... she just finished medical school and I said to her that the first night I slept with her grand-mother was on the wedding day... she said: "I'm more modern!" And well... that's life, things change... and I... little by little... I've been adapting to changes... I'm

moving along with changes... slowly... because if we do not adapt... I'll be out! It doesn't mean I always agree... but we respect each other... (P12)

In this excerpt, it is clear that autonomy is not a static congruence; it is also the need to move on, to adapt to changes, to be up-to-date, to keep participating in life. But adapting involves also a physical dimension: autonomy is keeping routines, adapting to changes and being able to ask for help whenever it is needed.

I am still the same person... doing the same things, decide what to eat, doing housekeeping, going shopping... the only difference is that now instead of coming with all those supermarket bags as I used to do... now I go twice a week... (...) And often I ask my son to help me with the bags... before I never asked for help... I carried heavy things and all... but now I have to ask it... because of my health... (P13)

Keeping daily routines seems to be relevant as well as adapting to less strength or less health. In order to do so, sometimes it is necessary to do things slowly or to ask for help from family or even to buy services.

My autonomy is to still doing my things, I cook for me and to my husband, I clean my house, sometimes I ask for help from a woman... but not always because my income is small... I like to keep my house. (P16)

This last option is conditioned by financial resources, as Patient 16 says, and it seems that financial resources are a concern to older people. To have financial independence is also a component of autonomy, at any age, in order to manage one's life, have a house and have access to essentials.

I would like that my son had enough studies in order to find a good job... and earn enough money... it is so important to have our own money... (...) because to me was the same thing... to have my money and to have my house, I have my own house. (P4)

In these testimonies, it is possible to acknowledge the relevancy of having a house and enough money to run it and to support a family. To have a house is the guarantee of freedom of movement and to continue setting the rules in one's own place: "I live alone and I have my house (...) I may come and go whenever I want' When I'm tired to be in other people's house I come back home." (P2) Further, autonomy requires having enough money to fulfil one's needs. But having enough money depends on having a good job during active life, and on having the right to



retire with a sufficient income which permits to keep having a dignifying life style: “Older people’s autonomy includes having enough money... for example, money for transportation... we want to go anywhere how may we go? We do not have money... retirement is short<sup>13</sup>.” (P8) And, for this, society, namely the state, has a significant role to play:

We live in a very retarded country. In other countries when people are sick they immediately have social assistance, some allowance... here not... since 59 years old I have had a cardiac condition and the doctor said that I should retire... but I was in hospital and after that one month at home and then I went to work... The state doesn’t help us. I couldn’t retire. The state didn’t allow. And we need the money to rule our life... (P1)

Hence, participants consider that autonomy also depends on social policies. Moreover, some participants state that in Portugal social policies are failing:

Autonomy is something that most Portuguese people do not have... [Interviewer: Could you explain it?] Well Madam, how shall we be autonomous if we do not have enough money for a part of our life? Autonomy doesn’t flourish in Portugal... Like Álvaro Cunhal<sup>14</sup> used to say “A few eat everything and others don’t eat anything at all.” From my individual experience it is true... those who have money eat and those who do not have money do not eat. In our country autonomy is a fantasy! (P6)

Thus, to these participants, without enough money to satisfy basic needs autonomy is no more than a beautiful word: “a fantasy”. Without material resources, older people lose autonomy, lose freedom and lose dignity. Hence, autonomy relies on both individual and social factors and it also means being independent on a physical and economic level.

To cope with financial issues may be a matter of “If we have little money we spend less and if we have more we may spend more” (P14). However, physical dependency is a worrying issue and it is related to the loss of physical strength:

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<sup>13</sup> The minimum retirement pension is nearly 250€ per month.

<sup>14</sup> A very well known Portuguese Communist leader since the time of the fascist regime, already deceased.

I was always independent... until I came here I never depended on anybody. I always did everything... before I came here I did everything (...) bathing, dressing up, and tidying the house... Shopping I didn't do anymore because I lost strength in my legs, but the rest I did everything... (P4)

Dependent? I'm dependent now, here... but my wife is even more dependent at home... I mean physically, not mentally, nothing... it's physically... now my son is our only hope... we must depend on him... he's my only hope... because I lost strength... physical strength. (P3)

Patients' concept of dependency seems to be centred on the physical dimensions and on the need for help regarding functional performance: it is the "being able to do" some tasks related to activities of daily living (bathing, clothing) or instrumental activities of daily living (cleaning the house, shopping). To be dependent means to need help from other people, namely children's help.

I just depend on me... but from now on I do not know... While I had a job I just depended on me but now I'm a widow and retired... my sons and daughters will have to help me as I always helped them in whatever they needed... that's why they are always prepared to help me... (...)Until now I just depended on me... but if I ever depended on them I would have to accept it... [Interviewer: What do you mean by dependent?] Regarding my legs, or to be in bed... I'd have to depend on them... I have no one else, right? (P1)

At the beginning of this excerpt the expression "I'm a widow and retired" seemed to point to financial issues. However, when I asked for clarification it was unambiguously stated that the issue was physical performance. To be a widow means having no spouse to help and to be retired probably means losing colleagues and friends: what remains is family; namely, children. Moreover, there is an explicit expectation that the help must come from children as a return for a lifetime's investment.

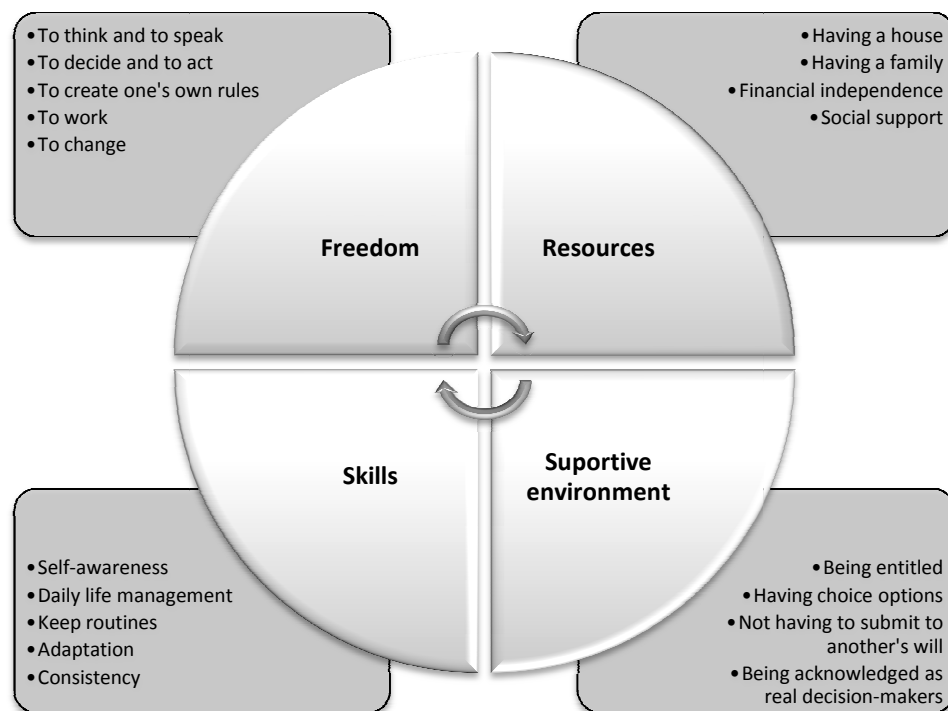
To face dependency may not be easy. Even if some older people's reaction may be resignation (e.g. "I'll have to accept it"), others may experience frustration or anger:

To be suddenly dependent on others... people feel anger... I was not expecting... isn't it? We need a bed pan... and they are busy... and people feel rage because we say... if I could stand up I wouldn't be asking for it... we wouldn't disturb. And the anger is not towards the nurse or the attendant... is towards me... I thought

that if I could walk I would go alone to the toilet and wouldn't need to ask anything of anybody. (...) It is to feel tied...And it is hard to disturb... (P1)

It is interesting to note that anger is not toward carers but related to the fact the help is now needed. Anger is a way of manifesting frustration related to dependency, particularly to sudden dependency. Hence, dependency in these patients' experience may be defined as being a concept related to task performance difficulties (either self-care or instrumental activities of daily living) due to loss of physical strength.

Figure 13 – Patients' concept of autonomy



From a review of patients' testimonies (summarized in Figure 13), it could be said that autonomy encompasses four axes:

- Autonomy is freedom – to think, to say, to decide and to act. It is freedom of movement, freedom to abide by one’s own rules, to work or to rest, to make choices and to change those options.
- Autonomy depends on individual skills – functional skills to keep up daily routines such as home management; cognitive skills to learn to adapt to changes, to develop self-knowledge, self-awareness and congruence over the lifespan and through different circumstances;
- Autonomy depends on external resources – such as having a house, having a supportive family, having enough money to supply basic needs and being part of a society that respects people’s right to dignity.
- Autonomy has a few external requirements – being legally entitled to make one’s decisions, having opportunities to make choices and not having to submit to other people’s command, i.e. not having to explain oneself constantly to other persons, either family or hierarchical superiors.

#### ***4.2.2. The meaning of power***

As the word “empowerment” does not exist in Portuguese (or a semantic equivalent), it is vital to be aware of semantic differences which may have a strong influence on analysis and interpretation<sup>15</sup>. Thus, patients were asked to

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<sup>15</sup> The Portuguese translation of the noun “power” is “poder” and it is simultaneously a noun and a verb. As a noun, it has the same semantics. However, the verb means “being able to” referring to having the skills, the physical strength or the authorization to do something. In the present conjugation it would be translated as “I can” or “I may”. The words “empower” or “empowerment” do not have an exact semantic equivalent. The word “powerless” is translated as “impotente”, which also encompasses two different meanings: if used with “I feel” (i.e. “I feel powerless”) it has the same meaning as in English but if used with “I am” has a sexual meaning and refers to the male impossibility to achieve an erection. Hence the words used were: to have power, to gain or to lose power, to feel powerful or powerless, to gain or to lose control over one’s life.

describe experiences related to having power or gaining power, what power they had in society, at home, in hospital, or even if power changes with the ageing process.

In patient's verbatim interviews, only a few excerpts were related to the meaning of power. At first glance, power is the possibility to keep ruling one's life and it is keeping the respect of others (namely, one's children) regarding one's decisions:

I think that older people do not have any power, only to rule one's life... and that's it. (...)I always owned myself, I proposed and disposed, even in my husband's time, I always decided everything... I proposed and disposed, I ran the house, and he was never a man that... that opposed whatever I wanted. I always owned my own life and often the other's life [Laugh]. The ordinary things, like ruling the house, deciding what to eat... ruling one's life... that's it. (...) I love things my way and I keep it. Often my son says "I do not do more because you don't allow, I never do things as you like!"And it is true. I like things my way. And that's it! (P13)

This excerpt suggests that, besides domestic power, older people do not have any further power. Moreover, even at a domestic level, it is necessary that there is no opposition. Thus, having power depends on other people to accepting this is so. Furthermore, in this excerpt, power may be defined as being able to do what was decided: it is to be aware of one's will and act accordingly. This patient uses a very popular statement in Portuguese: "to propose and dispose" related to having full power of decision and action. Actually, in her house everybody did things as she wanted both in the past ("in my husband's time") and at present (the son follows her rules). Thus, it seems that an empowered person is the one who has the power to set rules and makes the family abide by these. However, there is another striking detail in this excerpt: power at home belongs to women i.e. she always decided and her husband never opposed. Thus, she had the power over her life and over her family (husband and son). More testimonies reveal this home power of women: "At home we are both in charge... but I'm the one who's the master of the house... my husband eats whatever I give him." (P10) In this excerpt, another woman states that she is the master of the house. Furthermore, the expression in Portuguese "to eat whatever is given" is used in a figurative way to

express authority over someone. However these are women's testimonies. Hence I turned to men's testimonies and a peculiar statement was found: "At home power belongs to my wife. I'm the President but she is the Minister of Finance and Prime Minister... I just sign the pay cheque..." (P2) This is a very suggestive metaphor: she is the Prime Minister and the Minister of Finances, i.e. she has all the executive power. Another testimony corroborates this idea:

I think that I own myself... I own my own mind...It is having our own voice... but in my house my wife is the one who is in charge...she has more power than I do... Sometimes I ask to eat something but she is so stubborn that she cooks only what she wants... [Laugh] I have to eat whatever she puts on the table... (P5).

Thus, empowerment is being owner of oneself and having a voice; however, at home, he doesn't have this voice i.e. he speaks but she doesn't listen. In these examples, it is clear that inside the house power belongs to women: they decide how to organize routines, what to buy, what to eat, and what to do and men seem to accept it as it is. And this is stated both by men and women: P10 and P13 are women and they assume themselves to be the "master" and P2 and P5 are men and state that they are in a submissive role, signing the cheques and eating whatever the women want.

According to these participants, older men do not have any voice, either at home or in society:

What power may a 75 years old man have? None! (...) old people can't make strikes! Here in hospital, for example everybody gives orders and we have to obey! (P6)

Thus, besides the power to rule one's own life, older people seem not to have any power, because they do not have any mechanism to make their voices heard or their wishes attended to, e.g. they are no longer in a position to make strikes. As at home, where men may say what they would like to eat but women ignore their requests, in society older people are not heard, as their executive power is absent. Hospital seems to be no exception, as everyone else is in a command position, except patients.

To give orders and manage to be obeyed is also a condition of empowerment, either at home, in hospital or in a professional environment:

To give orders? To be bully? No! Look...I worked 31 years in the navy. The unit had three thousand men and I was in charge of 200. When I left some men cried saying: "only the good people leave!" Because I had the power but I gave the orders with respect, I was correct and polite... And when they had suggestions I listened to them... so they liked me. (P7)

The point here seems to be to earn the respect that makes people follow rules, by listening to people and by being respectful in relationships, without having the need to use authoritarianism. However, it is necessary to underline that P7 was in the navy in a position of command: he had hierarchic power. Nevertheless, his testimony shows the difference between bullying, authoritarianism and congruent empowerment in a humanized environment.

Thus, empowerment relies either on having hierarchic power or on being acknowledged as having the authority to make a certain wish respected. Furthermore, having physical strength also influences individual power: "As long as we have physical strength we keep the power to do... but ageing takes from us the power to do as we have the will but not the strength to do it." (P3) In other words, whenever older people keep physical strength they are able to get decisions accomplished. But whenever physical strength decreases, the older person moves to a dependency situation: they make the choice but depend on someone to execute it. Thus, it is necessary to have a voice, to be listened to, to be respected; otherwise, the only possibility is to have some kind of authority such as hierarchic power.

Hence, older people relate power to decision-making freedom regarding one's life and as well as to the necessary strength to execute decisions. Nevertheless, sometimes this power is delegated to someone else:

Power belongs to people we love and who love us. For example, my brother whom I really love, because I'm his sister but also a little his mother...I was eleven years old when he was born... If he says "You'd better do it this way» I think twice... it is not that my idea was wrong... but to avoid hurting his feelings...

(...) from one side it is like an advice from someone who loves us, but on the other side we may give up our will in order to accomplish their wishes, to not hurt them... (...) When I'm not well I pass everything to my brother... I trust that he will do the best for me. (P2)

According to this testimony, in some situations (such as illness) power may be transferred to other people. In this context, "When I'm not well" may be interpreted as "when I'm ill" or "when I feel down", reporting a situation of vulnerability or frailty. In these conditions, decision-making power may be relinquished towards someone trustworthy, a very close loved one. Moreover, in this testimony there is a clear difference between asking for advice and relinquishing decision-making power. In addition, it is also clarified that sometimes the older person is able to decide but accepts other people's decision to avoid hurting other people's feelings. However, in other situations, decision-making power is transferred to someone trustworthy: a family member, someone who loves, knows and will do the best for the older person.

Hence, from an overview of participants' testimonies it looks as if empowerment may be defined as the possibility to rule one's life according to one's wishes, rules and patterns, having the physical strength to do so or the authority to make others accept and accomplish these decisions. In labour contexts, authority seems to be related to hierarchic power but in family contexts needs to be accepted and acknowledged by all members. Moreover, participants consider that older people do not have any kind of power in social contexts. In the family context, women are more powerful than men. Finally, in some situations of frailty, power may be voluntarily transferred to someone trustworthy.

#### ***4.2.3. The influence of ageing on autonomy and empowerment***

The issue of ageing and to what extent this influenced autonomy and empowerment was often brought to conversation. According to participants, there is a lack of respect towards older people: "They look to me as an oldie, isn't it?



(...) Some people laugh at our difficulties.” (P3) Moreover, older persons are often considered useless and a social burden.

Today, there is no respect for older people (...) the young want the aged to die as quickly as possible to take their retirement payment away. They do not want to pay retirement pension, the sooner the better... it’s just ring the bell and hurry up! (P6)

This excerpt raises the issue of being a financial burden to society. The metaphor “ring the bell” is related to the announcement of death that was used in the past: the church bell rang each time someone died to call mourners to the burial service. And the “hurry up” expression suggests that this is a quick movement: there is no time for tears or ceremonies. But besides testimonies about old people’s being considered a social burden, some testimonies evidence some loss of respect toward older people:

To the extent we’re ageing we lose... we must submit to more and more social issues... some of them deleterious... for example... we do not have money for transportation, we should be entitled to travel with a special pass... if public transport allowed older people to travel for free ... Another issue is in public services reception: as they see us it’s immediately “here comes the pain in the ass!” Attendants do not have the due education, they forget good manners... formerly elders were respected... I remember in my father’s village, older people were respected... is doesn’t mean that everyone abided by their will but listened to their advice... nobody dared to turn their back... Not as we hear now... “Here comes the oldie!” (...) Even on television... only new is good... new people, new things, new technology... old stuff is trash... Whatever we say, our experience... it doesn’t matter... It’s old so it’s trash! (...) This society undervalues older people... Now we’re the grannies... people do not look at us (...) this is education at home... foundations for good education are lost... (P8)

This excerpt reports the perception of being considered less respected in a society that values the young and the new. Social values have changed, as disrespect is replacing civility and good manners. The reasons pointed out are related to parents’ education at home and to the non-existence of political will:

When I look around I realize older people do not have any power in society... but they could have... if there were political will... It is the will, the will... politicians should lose the arrogance... the haughtiness... they should look ... to structure society in order to avoid this look to “the little-poor-oldies”, who do not know a thing... that can be manipulated as a crop.... (...) But it is difficult to change

because... unless a very important politician gets really old... otherwise... we will stay... (P8)

According to this patient, there is no social attention towards older people and their participation is not valued. As stated before, older people do not have a voice as they are no longer in a position of causing strikes or influencing society in order to change things. The social environment does not help older people to keep their sense of self-worth. And for older people this does not make any sense as “Ageing didn’t change anything to me. I’m still the same.” (P10) Despite physical changes, personality and decision-making patterns do not change.

Autonomy to me is the same thing, nothing changed.... But each one is different... from person to person... some people are unhappy but they already were when they were young... some people are 92 and are happy... I think each one keeps his personality... in myself... I do not see any difference... some people are stubborn but they always were... (P2)

To these patients, it is clear that ageing does not change personality: they continue to be the same person, have the same mind, each different from any other person. What changes is not who they are but what they are able to do: “What changes is that we have the will but we do not have the strength... we want to work, but we are not able to do it (...) because physical strength goes...I want to do but I can’t do” (P3). Thus what changes is not the person, but the physical strength.

Ageing to me... what changed is that I do not have any utility... My mind I have, and I know a lot... Even yesterday my wife said that my in-laws had a problem with the water-heater the water was getting out cold and dripping through the wall... And I said immediately that the “boiler” blew up... but well, doing the things I can’t anymore... I feel useless. The will remains but the strength goes... (P7)

Patients shared many examples of lost physical strength with consequent need to adapt activity patterns or to reduce work, which may lead to feelings of uselessness and powerlessness:

Ageing is difficult... we lose memory and we lose strength... we go somewhere to pick something and when we’re there we do not remember what for... and we get tired of doing the things we did before... cleaning and carrying things... (P16)

Ageing is difficult because the same personality lives inside, the same will, the same decision-making skills, but the strength to do things reduces. Moreover, this

strength reduction may be aggravated by illness: “Sometimes illness puts us down... makes us older and makes us lose autonomy... but I didn’t lose anything so far... but illness is...” (P11) Illness has a significant impact on older people’s lives:

Illness takes from us some self-esteem, some decision power... we may lose some decision power because we lose some objectivity, when I’m ill I miss the strength that I have when I’m healthy. No matter what illness may be... we lose some will to decide... and here in hospital even more... (P6)

Thus, it seems that independently of a specific disease, when ageing is accompanied by illness and when illness requires hospitalization, autonomy really changes. Nonetheless, without serious disease, the most significant differences are in work capacity, which is a determinant of retirement and consequent reduced income:

Nothing changes; only if we want. (...) My life is the same... the only difference is that I’m retired. (...) Well, it is not exactly the same thing as I have less money... I can’t buy so many shoes, or clothes... but I succeed to manage myself... (...) something that changes with age is that we are no longer able to work... I loved to work but now I can’t anymore. I do not have the strength (...) financially it is not the same as retirement means less money. (P2)

To keep working is important to older people as retirement has a financial and psychological impact. To financial changes older people are able to adapt. One participant uses a Portuguese saying: “No money, no addictions...” (P12). But psychological effects are expressed by the frustration of facing the loss of physical strength. As P2 says “I loved to work but I can’t anymore”. Also the example previously given by P7 is significant: he express his frustration related to being able to identify a problem in a home appliance and not being able to do the necessary work.

Hence, having the will but not the strength seems to be a cornerstone of patients’ well-being and a possible source of frustration, reduced self-esteem and disempowerment as well as disengagement attitudes. And P5 also has a sentence mirroring these feelings: “Time and years put us down...It’s like already having our feet in the grave” (P5). However, something else is present in this sentence:

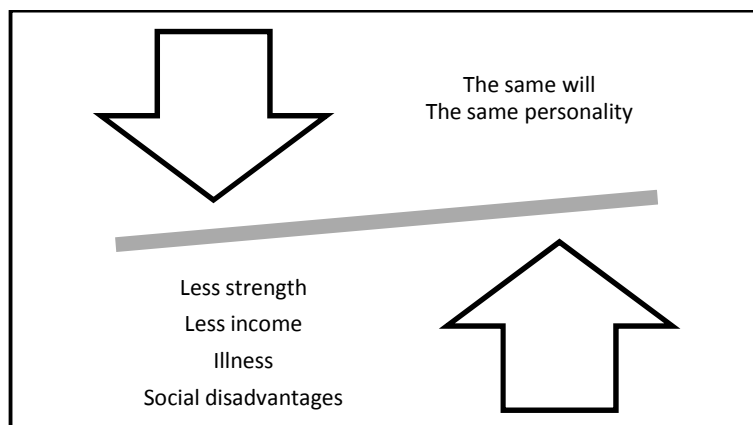
thinking about death. The expression “feet in the grave” is currently used in Portuguese to express the idea of a close death. And, in fact, the idea of a close death was present in patients’ discourse. According to some testimonies, as age goes on the old person frequently thinks about death, as each day lived is a day less to live: “I think that my days are over... it has been far but now death is closer... Well... people know... each day ahead, each day closer... the end is near!” (P6) And according to some patients some concerns may change:

When just think of eternal life at a certain age. And that’s it! We pray a lot, pray to the Lord, to the Virgin Mary, and to everything... and we put our heart together with The Highest, do you understand? And there we go... and we go on living thinking of Him until He calls us... (...) I think of thousands of things... but I’m always thinking of The Highest... I think of dying and of going to the Lord... (...) when we are young we think about family but when we become old we think about the Lord. (P4)

Thus, at a younger age, people have other concerns, such as family. But, as time goes by, older people are aware that the end of life is closer. Nevertheless, patients do not relate end of life to autonomy or empowerment issues.

Reviewing patients’ testimonies about ageing, it could be stated that the most significant issue is managing the balance between keeping the will and losing the strength, as drawn on Figure 14.

Figure 14 - Ageing challenges according to patients’ point of view



Furthermore, some key issues brought by participants were:

- The personality does not change: “I am the same!”
- Decision-making patterns do not change: “I’m able to decide as I always did!”
- Without mental impairment, the will remains and the only changes are the ones each person determines: “I know what I want!”
- Ageing brings physical strength reduction and consequent retirement: “I am not able to do as I did.”
- Retirement means reduced income with consequences for daily life and autonomy: “Less money is less quality of life!”
- Social values diminish older people: “Society considers that we are a burden!”
- Illness and hospitalization change autonomy and empowerment: “I do not care or I do not want to decide.”
- A supportive environment (family) helps to keep autonomy and empowerment: “Nothing changes because they respect me!”
- Ageing makes people think about death: “I know that my days are over!”

#### ***4.2.4. The experience of hospitalization***

Looking at patients’ description of hospitalization one of the first things that captured my attention was that over and over again patients said: “I was always well treated... I had good doctors and good nurses.” (P1) And in almost all interviews it is possible to find somewhere expressions such as: “They are all very kind” (P16) or “They are all good professionals” (P4) or even “They treat us very well” (P8). However, after expressing this initial compliment, the discourse changed. Patients started to criticize hospital, saying that “There is nothing worse

than to be in a hospital... this is like a jail... is deportation". (P4) Moreover, patients expressed some perplexity as they "(I) do not know how some people like to be in hospital... some people do like!" (P2) Thus, it seems that professionals are good but hospital is not so good. In fact, to P4, to be in hospital is like being in prison. But to P11 prison may also be disease. "In hospital we are a little tied to the illness... serious or not we are tied." However, having an engaged family is helpful in keeping autonomy and, in addition, nurses have a significant role to play in allowing patients to be with their family:

When I started to walk it was freedom. I have 8 daughters plus in-laws and grandchildren... It is too many people to visit me... and I started to go to the atrium to see them all, I asked the nurse if I could go outside and she said "yes madam, go as you wish!" They are very nice. (...) And my daughter who has a store she only comes here by 9 pm... And she asks and the nurses let her stay until 10:05 or 10:10 pm. After that of course people want to sleep and nurses say "It's time to go!" Nurses are very nice. (P1)

Physical freedom seems to be important not only to get out of bed but also to walk outside the ward doors, in order to receive more visitors. Again, in this example, it is underlined that nurses were very nice. Thus, I kept looking through narratives, trying to find what the reasons were that made patients feel as if they were in prison.

In other countries is different. I have a friend in the Netherlands, she works in a hospital, and there they have many more professionals, more staff. And the attention towards patients is different...it is better. They have more nurses. Here I was once in a ward and 12 hours passed without seeing a nurse. (P1)

In first place, the issue of shortage of nurses was found. In fact, twelve hours without seeing a nurse is a very long period. Nonetheless, it seems that patients understand this shortage of nurses and the need to wait for care:

Some people think that someone has to be near them all day and all night. It cannot be because we are so many... And staff is short, we know... but some people only see their own side... Well I do not see things like that... I'm treated and then someone on my side may have another different disease, may need some more attention than I do, isn't it? At first I had to wait for my turn to be cared for, for someone to wash me... but I always understood that I was not alone... there are more patients to be cared for and my turn will come... (P1)

Hence shortage of nurses is not enough to explain why being in hospital may be such a negative experience. Therefore I looked again at the data.

How shall I say? There are professionals and professionals... some are real ones... other are there just for the payment... Some want to work, others just do the job... some look to us, others... do you understand? (P3)

The answers started to come: after all, it seems that not all professionals are as good as they should be. Some professionals do not care for patients and are just concerned with the payment. One patient goes even further, stating that sometimes it is necessary to give some gifts to get full attention:

In some places, not here, they care for the money, not for the people. And if we are sick and old and above all if we are poor... it is a kick in the ass... Not here, but in some places... they are waiting for the gifts... a lamb, a turkey... to have access to care, to hospital to a consultation... if we have no money we may suck on our finger and we are treated like dogs! (P14)

This is a very strong descriptive statement. But it looks to be a past experience and it is underlined: “Not here!” But the idea shared by these patients is that money is relevant to have adequate care: if in the previous sentence it was stated that some professionals work for the salary, in this example some professionals define care according to extra payments from patients. Furthermore patients may be judged by their economic status:

Not here, but in ER old people are not respected. [Interviewer: What do you mean?] Well... particularly people with less money are abused... [Interviewer: How?] Well... nurses yell, yell! “Shut up! Shut up!” But if patients shout is because they have pain, or because they want to piss... “You have to wait! You have to wait!” But often we cannot wait. And sometimes our mind does not want to wait... They should be different, like here... when we ring they come immediately and if one nurse is not available she asks another colleague. They should be more polite, tenderer. (...) We keep waiting, and waiting, and seeing things around us... I saw a men shaking and shaking and moving his legs and they shouted: “stop it!” Then I saw a doctor to close his eyes and the nurse moved the bed away from my sight... Then I saw them taking him away and I asked what happened... And I thought why were they shouting if they know he was dying? They should be more... well... (P16)

This patient seems to be saying that some professionals judge patients according to their economic status. It is not explained what will be better for the wealthy people but it is suggested that the older and the poorer do not receive adequate or

respectful attention. But again this patient states: “Not here!” i.e. “in this ward nurses are polite and respect us”. In other words, nurses should be able to listen to patients’ needs and to care adequately, establishing a humanized relationship. Looking through patients’ testimonies more examples of lack of attention or inadequate fulfilment of a patient’s needs are presented:

There are here many people who think I do not understand... Don’t they think I am foolish because I am not, Thank God! I was never foolish. And I see many things... But they cover each other do you understand? But I have no complaints... I’ve been well treated... But there is nothing worse than to be in a hospital (...) I close my eyes... to help passing time... I pray, I read... and my son visits me... and so the time is going... (...)I was a little disturbed in my bowel... and I needed to call many times and they told me off... But it was not my fault... I had diarrhoea... and they complained to clean me so many times... (...) time in hospital is slow... I’m desperate to go home (...) I’ll manage myself at home. I need to go home. This is hell. (...) Yesterday I had to eat with dirty teeth... And I do not like it at all... It is very difficult to eat with dirty teeth. Now they are tidy, my son came here and washed it (prosthesis) and I feel much better. (...)‘I asked many times since I’m here that I would like to receive the Holy Communion... but no one gives it to me... I do not want to die without it... but no one listens...(...) At home I went to the church and had the Holy Communion every single day...Here...I’m here for fifteen days ...and nothing. And it is very important to me, you know? (P4)

In this excerpt, different issues captured my attention. Firstly, the patient’s awareness of what is happening. This is an eighty-year-old lady who very clearly says that even though she may sometimes have her eyes closed, or even if she looks too old she is perfectly aware of what is happening to her and around her. In the second place, there comes the statement that she has no complaints. She affirms she is satisfied with care but afterwards she corroborates other patients’ opinions, saying that there is nothing worse than being in hospital. Finally she describes nurses’ inadequate behaviour (they told her off owing to her diarrhoea) and her unfulfilled needs (oral hygiene and spiritual needs).

One came here and decided not to help me to go to bed and turned away... And I’m still here with a needle on... sticking on my arm... (...) I asked the lady for help, to move the pillow to the right as I couldn’t do it and she did reply in a very rude way... This is not a professional behaviour... it is not! And if they arrive here and find me doing my needs [urinating] they even laugh... And there are things



that I do not say because I'm afraid to be told off, or criticized. There are many ongoing things, true things... even if unseen, the truth will emerge. (P3)

In this example, the patient's needs were ignored and, furthermore, he was told off for calling. But, in addition, this patient clearly states that there are other things that he will not say because he is afraid of retaliation. To go back to the P4 excerpt, it is possible to interpret also this fear when she says: "I see many things... But they cover each other do you understand? But I have no complaints... I've been well treated". In other words: many things happen but it is better not to tell. One patient even says:

We come sick and go even sicker! This is such a mess... You do not know the hell down there after the ER.... I came in with a disease and leave even worse... I saw creepy things... spine-chilling... a very old man it was a muddle... and an old woman... everything exposed... I had to... you see, we [patients] have to support one another... (P3)

Thus, patients experienced and witnessed too many things that made them feel worse, not owing to disease or medical procedures but inhuman behaviours: lack of adequate care, staff's unethical, and even rude, behaviour, leading to patients' fear to call for help. To cope with this scenario, some patients close their eyes and try to sleep: "Here I try to sleep in order to help time to go by quickly. While I sleep I do not think. Otherwise I see nothing to help" (P6). Other patients pretend to be asleep, think of family, pray, try to ignore things and do not formally complain:

I think of my family... I have my wife who is sick; I have my daughter travelling from Africa... I close my eyes to pass the time, to think... sometimes they think I am asleep but I'm not.(...) Some people here talk about the elderly in such a rough way... some of them would beat us if they could. Patients call and they pretend not to hear... they do not care about us at all... (P5)

Furthermore, than that some patients even try to be invisible, i.e. not complaining, not disturbing: "We do not like to disturb" (P1) trying not to call and keeping silent, which is very much appreciated by nurses: "Well... someone yells... another one yells... and a nurse did say pointing up to me "look at him, he's here for four days and nobody hears anything." (P7) The good patient does not complain and does not call for attention.

As far as power is concerned, patients believe they do not have any power at all.

Having power? What power? What power may we have in hospital? (...) Here everybody gives orders and we have to obey. (...) Patients have to obey. We do not have any decision power. (P6)

But one of the reasons may be because patients relinquish all power and abide by professionals' rules, as nurses and doctors have some knowledge patients do not have:

In hospital everybody gives order, doctors, nurses, attendants... [Interviewer: And patients?] Patients have to obey! Nurses and doctors know what is better. We have to respect their will. They have the knowledge. (P13)

In these examples, it is stated that patients must obey physicians' and nurses' rules because they have the knowledge and want to keep the power. But although sometimes nurses and physicians are referred to together as a whole, looking to patients' verbatim statements it is possible to identify some differences:

I think I always owned myself... but in hospital? No, No! They do not want to! Doctors and nurses and that's all. There we definitely lose the voice! (...) We eat whatever they give us and we do the treatments they prescribe! (...) But they are all very nice, very kind, doctors and nurses (...) Patients are so many that they cannot give a hand to all at the same time. (...) Here I cannot look to my beard... I used to shave every day... but here nobody does it. I cannot look in the mirror. (...) I do not like to be here... I'm stuck... I do not have freedom. (P5)

Hence, physicians have the power over treatment because they have the knowledge while nurses have the power over hospital rules and patients' daily life.

Regarding disease, doctors decide, we should not interfere. [Interviewer: Why?] Because we do not have the knowledge to discuss it! They must decide and we must obey. They know what the best is for us! (P11)

In these examples, patients state that physicians' power is related to having the knowledge about disease and treatment options. Thus, they must decide and patients should accept. Nevertheless, patients would like physicians to talk an understandable language.

Sometimes I stay listening to their language to see if I understand it... often we are unable to understand it... then I ask my family: I think that I'm going to do this or that... (P2)

Furthermore, patients like to be informed in a way that allows them to be in the right condition to sign a consent form, as, without information, there is no informed consent:

I will have surgery. Doctors decided. [Interviewer: Did anyone ask you anything?] Well, in these situations is to live or to die... there is no choice. (...) but I liked the way the Director came here... he more or less... he gave me a light explanation... and here I am! (...) You know we are like prisoners in this place... and after all we may be here for eight, ten or fifteen days and we know a little about what is going on... (P6)

Besides, sometimes doctors show options that are not seen as real options:

The doctor once said to me: Mr Elias you ought to have cardiac surgery. You're at life risk. But surgery is also a risk. Do you want to do it? And I said: Yes! What else should I say? It was to die in a few hours or to take the chance. He asked my opinion but I really had no choice if I wanted to live more. I liked that he was clear, straightforward. (P7)

Thus, it looks as if the only option presented to patients is between living or dying in a short time. Hence, patients accept physicians' treatment proposal as they do not have the time, the knowledge or another solution.

Nurses' power is quite different: the issue is not about living or dying but how to manage life in hospital. Patients also state that nurses know what the best is for patients. However, according to their own point of view the best for patients seems to be needs' fulfilment and respectful relationships:

In hospital we must follow nurses' orders. Because they decide whatever is best... for us, you know? But sometimes it is necessary that nurses understand patients... and sometimes there are different personalities... and the patient does not want something and they argue... conflict, you know? It is necessary to have mutual understanding. (P12)

To P12, it is clear that patients must follow nurses' rules; however, it is not necessary that those rules are imposed independently of a patient's will. It is necessary to have negotiation, mutual understanding. However, patients' testimonies are full of examples of nurses' authoritarianism:

It happened a few times that they came with the lunch tray and I didn't want to eat... [Interviewer: And what happened?] They made me eat it! They insisted... (P10)

Forcing people to eat is one common example of imposed action. Moreover some patients talk about the need to follow rules. However, there is not any hospital rule saying that the patient has to eat a particular amount of food. Nonetheless, many patients talk about this imposition. Other situations are also presented to describe a patient's disempowerment:

In hospital I feel limited... there are rules for patients to follow (...) I'm ninety years old and I'm in hospital. Particularly because I'm in hospital I can't say what I feel. Precisely! I have to say "Yes!" There are things that I would like to say, but I can't! I can't because I'm afraid... I'm afraid to say. So I think but I do not say it! (...) In hospital everyone gives orders except patients... I feel anger, I do not feel free [Interviewer: And why?] Well Madam, if I say that I want to go to bed and you say: "No, you won't, because I want you to be here" I have to eat and to close my mouth. In this and in many other examples! That is what I think! Do you understand? We should have the right to be free, even to make mistakes! (P15)

In other words, it may be stated that nurses have the power to control patients' movements and patients' freedom. The consequence is submission ("I have to eat and to close up my mouth"), anger and the feeling of not being free. Thus, the prison that patients talk about seems to be the prison made by nurses, the deprivation of older people's rights: the right to talk, to disagree, the right to be in bed or sitting in a chair, the right to eat or not, the right to shout, to complain, the right to be free and to make mistakes. And this prison is worse than illness or bed resting as it is related to human rights: the right to be a person, treated like a human being and receiving dignifying care. P15, in his interview, poses the question: "what can a ninety years old man, sick and tired, against young and healthy nurses in their white smock?" Thus, it seems that older patients in hospital feel powerless and that nurses are one of the main causes of powerlessness, as often they do not listen to patients' needs.

Nurses also make their decisions... and decide what we must do... now you have to bath, now you have to eat... and it's fast... let's go you have to eat! And we quit complaining! [Interviewer: Why?] Well, we are afraid... And some people if they do not have fear now they already had it. There were times when we could not even open our mouth. Now it is a little different... but it is a long way to listen to patients... (...) we lose dignity because people didn't learn civility ... we are tired and feel powerless... and it is normal to quit. But we should be cared for with

dignity... Doctors and nurses make the decisions... you know? Poor will be poor and rich will be always rich! Do you understand? (P6)

Hence, older patients would claim dignity, if they had a voice. When P6 says “There were times were we could not even open our mouth” he is clearly pointing to the fascist regime in Portugal when people were put in jail just for disagreeing, for no matter what. However, it seems that they also feel voiceless and even though Portugal is now a democracy there is a long way to go until older patients succeed in being heard. The fear to talk is present, dignity is lost and civility is forgotten. By saying “Poor will be poor and rich will always be rich”, P6 is probably saying that powerful people will be powerful and the powerless will remain powerless. Many testimonies support this interpretation of powerless patients facing powerful professionals. Moreover P8 gives a very accurate description of his experience of hospitalization and, regardless of its being a very long citation, it is worth presenting as it summarizes many issues reported by almost all patients:

Only a few patients in hospital have their own individual power... to ask for something or whatsoever... Patients should have power, should seek to have power... as a citizen I think that I’m entitled to have it. Patients should require to be treated as... to be considered as partners... like colleagues (...) as patients often are under a certain professional despotism, authoritarianism... some physicians, some staff sometimes considered themselves outstanding... they think they are above everything and everyone. It is “I may, I want, I order...” it looks like we have to do whatever they say and keep quiet... and that’s it! But no, we should not have to... It looks like when we come to the hospital they think we are not be able to think... (...) But in a few circumstances it is just a matter of organization [Interviewer: Could you give an example?] Bathing... it is not possible to have patients to bath all the day, one before lunch another after lunch... This should not be like... imposition... but good management... it is important to explain to patients what the rules are (...) at home we also have rules... in a democratic society there are rules and we must accept it as we accept the train schedule... (...) And if they explained me I would understand that I have to get up from bed, or to bath... if explained... but not if it is just because they want or because they say... if they say “you have to stand up because I want to!” if that is the case I do not accept it... But sometimes orders are out of mere caprice ... and it leads to

conflict. It is not good! When someone imposes rules that nobody understands... (...) Generally they do not explain much... Not much! I don't know why... maybe because they like to keep knowledge. The hierarchic chain, let's say it, likes to lead trumps<sup>16</sup>. (...) Patients should know exactly what is happening, step by step, what rules, what medications, what treatments... we should know. (...) Sometimes they have the protocol to inform and give us a form and say "Read this!" And we read it but we feel so perplexed, that often we are unable to understand in that particular moment what we are reading... As often the language in the forms is mixed... current language and technical terms and we do not understand. (...) I think it would be vital that nurses and doctors really tried to help patients understand those things... (...) It is more than just giving the paper to sign... It would make all the difference! (P8)

Older patients' experience of hospitalization and their need for empowerment is perfectly summarized in this excerpt:

- To keep patient's power should be considered as a citizenship right;
- Patients should develop a proactive attitude in seeking for power;
- Patients should be considered as partners, as good care is possible through negotiation;
- Health professionals have authoritarian attitudes and behaviours considering themselves entitled to assume decisions and control;
- Patients are able to understand the difference between routines related to organizational management and blind rules that are just power expressions from health professionals;
- Patients feel that they must be silent: obeying and not complaining;
- Professionals should give patients enough information (in an understandable language) to allow informed consent and to enable patients to participate in care;

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<sup>16</sup> Referring to the metaphor of playing cards and hiding the trump cards.

- Not sharing information with patients is a way of maintaining professionals' power and patients' disempowerment.

To outline patients' testimonies, it could be stated that the experience of hospitalization is described as a disempowering event where nurses play a key role. In a first approach to the verbatim statements, an apparent contradiction emerged: professionals are very good but hospitalization is a terrible experience. Moreover, it is stated that nurses' ratio is shorter than it should be. However, nurses are described as being outstanding and knowing what the best is for patients. Often it is argued that some inadequate things happened but "not here" or "not to me", suggesting some fear to talk that is subsequently confirmed by many patients.

Being in hospital is compared to being in jail, where individuals are deprived of freedom of movement and controlled by severe rules. In hospital, older patients feel powerless: on one side, physicians have the knowledge and the decisions regarding life and treatment; on the other side, nurses keep the power regarding daily life issues. As far as physicians' power is concerned, patients do not feel upset because decisions made by physicians are not usually made by patients in their daily life. Whenever older persons are ill, they go to the doctor and follow his prescriptions. At home, patients do not usually make life or death decisions, thus in hospital the difference is not so notorious when physicians assume control.

However, with nurses it is different: in hospital, nurses hold the power patients had at home, such as to decide where to go, what to eat, when to have a bath, what to dress in, and what to do. Hence, the freedom patients describe as having at home is the freedom to be ruled by one's own rules, the freedom to think and to express feelings. Thus, the prison may be the other people's will, mirrored in patients' reports about nurses' authoritarianism.

## 5. DISCUSSION

After presenting my interpretation of nurses' and patients' points of view the endeavour is to present a comprehensive overview discussing similarities and differences and, by doing so, to provide an answer to the research question: How do nurses and older people experience autonomy and the process of empowerment in hospital?

Summarizing the nurses' point of view, it could be stated that autonomy is to rule one's life, to live independently and to make free choices, having control over the human environment. Moreover autonomy encompasses the necessary physical skills to perform self-care, i.e. to participant nurses autonomy is strongly associated with independence in the activities of daily living. In hospital, nurses assume that once physical strength is lost (or significantly impaired) older people do not have autonomy. Hence nurses assume decision-making power on a patient's behalf. Empowerment is a largely unknown concept but nurses are able to identify disempowering practices in hospital. Nonetheless, besides feeling some indignation towards patients' disempowerment and reduced autonomy, nurses fail to assess and to address their needs.

According to older participants, autonomy is a broader concept, strongly dependent on the human and social environment. It encompasses freedom to be oneself, to abide by one's own rules, to make choices or even to make mistakes. Autonomy requires individual skills, such as functional skills to maintain daily routines, but, particularly, cognitive skills and the willingness to maintain self-awareness, to learn and to adapt to changes. Furthermore, it includes having opportunities to make choices and not having to give justifications to other people. In hospital, patients report losing all the power they have and they express anger and frustration as their skills remain but freedom of agency has been completely lost. As far as decision-making is concerned, patients have different perspectives vis-à-vis nurses and physicians. Regarding medical decisions, even if



patients would appreciate it if real informed consent were sought, they feel comfortable with the paternalistic approach, as physicians are considered to have the knowledge and the experience to decide. However, regarding nurses' power, patients do not feel comfortable with the paternalistic or even authoritarian approach, as nurses' deprive patients of their autonomy; namely, in decisions regarding daily life issues, which patients feel perfectly capable to make.

Hence, it is vital to discuss findings, confronting points of view and the literature in order to search for a broad understanding of older patients' autonomy and empowerment in hospital acute care. And as this is a piece of phenomenological research, participants' "situatedness in history and in time" is important, as any outcome is the result of the interaction between participants and their environment (Koch, 2006, 1994).

Thus, if the aim is to explore older people's experience of hospitalization, it is important to discuss who these older people are and what happens in hospital. Therefore, in the first place, I will present older people, who they are and what their background is. Subsequently, there will be a discussion of what is happening to older people in hospital and, finally, I will discuss the concepts of autonomy and empowerment and what this thesis adds to knowledge.

### **5.1. Placing action in context: society, family and older people**

It is important to remember that this study considers different kinds of older people. Firstly, older participants describe their own experiences, while nurses talk about people they have met. Secondly, the time and place varies as nurses describe older people in different settings and at different moments: at home and in hospital, i.e. older people from the nurses' childhood, in their own environment, and older people from the present or from the recent past whom they cared for in hospital. Older patients who participate in the study also talk about their life prior to hospitalization and about their experience of hospitalization.

Thus, narratives encompass past and present dimensions, health and illness situations, home and hospital events and different subjects (“I” and “they”, “me” and “the others”).

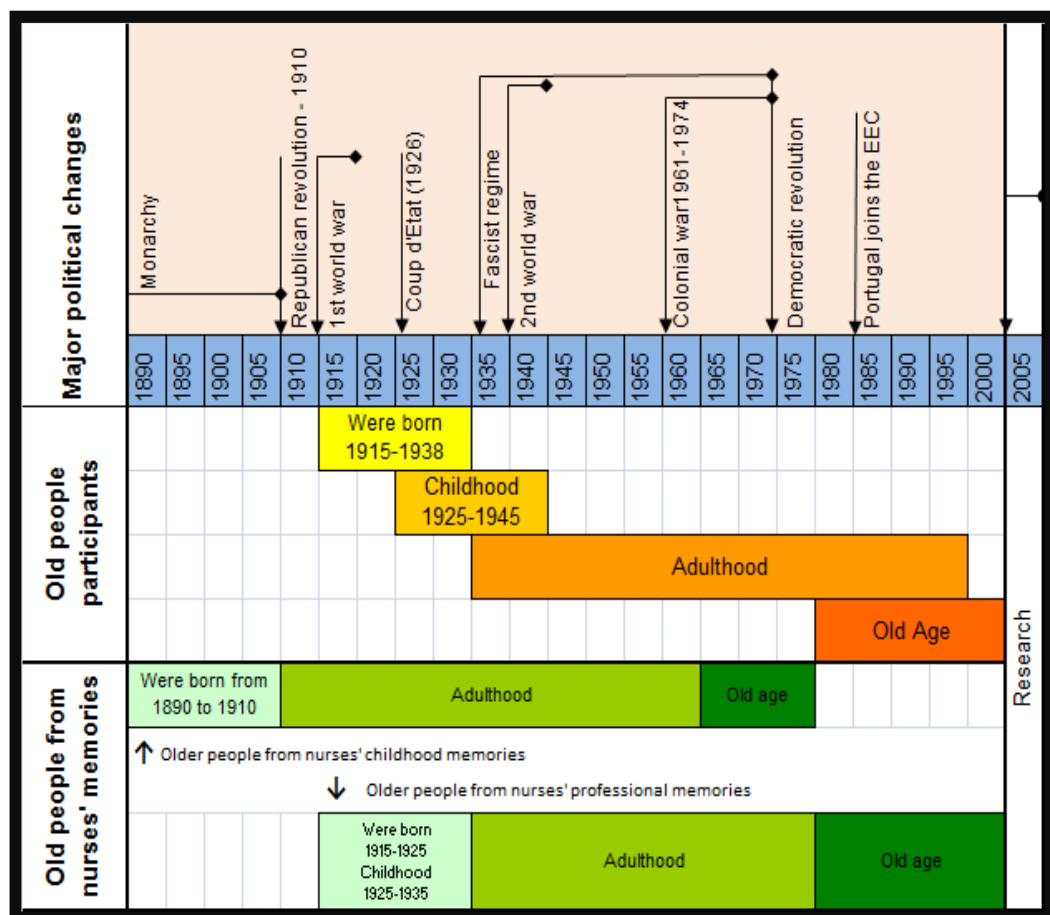
Moreover, while older participants (aged from 67 to 91 years old) were born between 1915 and 1938, nurses describe older people from different generations: great-grandparents they had forty years ago, grandparents from their childhood, or even their present parents, in-laws or grandparents. Although age is sometimes mentioned, the exact birth dates of these persons are unknown. Nonetheless, considering that participant nurses were aged from 30 to 45 years old (i.e. were born between 1960 and 1975), they may be talking about people that have been born from the end of the nineteenth century (1890) up to the 30s of the twentieth century (1939). Therefore, older people portrayed in this thesis may belong to different generations. However, as age is not usually mentioned in the nurses’ data, it is also important to keep in mind that, to a child, the grandparents are “old people”, even if they are fifty years old. Nevertheless, it is not necessary to look for very accurate dates but just to have an idea of the placement of the stories in history relevant for the hermeneutical work (Koch, 2006, 1994).

Hence, older people described in this scenario may have significant differences, as the time gap may reach fifty years, i.e. some were older people in the decade of 1960s while others may have become older people just in the twenty-first century; perhaps also to be old in the decade of the 60s or 70s would raise different issues, as society had changed. However, first and foremost it is important to acknowledge that social changes are relevant not only to understanding older people at a particular moment of their lives but also to understanding that social changes have shaped everyone’s life, nurses included. Furthermore, in the last decades, Portuguese society has experienced dramatic changes, both deep and fast changes, as in less than four decades even if we have the same country we have a very different society (Barreto, 2002).

### 5.1.1. Major political changes in Portuguese contemporary society

Although society changes continuously there are some significant events that may be major turning points. Thus, Figure 15 summarizes what I considered to be major changes in Portuguese political and social life, vis-à-vis the different generations of older people.

Figure 15 – Major social and political changes in Portugal during the twentieth century



Portugal was a constitutional monarchy up to 1910, when a revolution of liberal ideas took place and the republic emerged. However, the First World War and other social conflicts occurred, opening the way to another revolution (1926)

which pushed Portugal into an oligarchic regime. This revolution led to fascism that stayed for 48 years, up to 1974. Two wars had a significant impact on Portugal, even though these happened beyond Portuguese borders: the Second World War (Portugal sent food and supplies, leaving people in situations of poverty) and the colonial war in Africa, where, according to fascist regime, Portugal was defending its land and interests, but where a large percentage of young men fought against native populations to impose white domination and fascism (Reis, 1996, Barreto, 2002).

Considering issues of self-determination, freedom and autonomy, it is imperative to note that participants in this study (older patients) lived a significant part of their lives under an oppressive regime and even if they were born before it, all their childhood and adult life was lived in a system where individuals did not have the right to express their ideas and nobody had freedom of speech. As one patient said “maybe today some people do not face fear... but they faced it in the past.”(P12) A culture of obedience was deeply imprinted on people’s behaviours, as described in the Foreword. In those days, political police forces did not allow anyone to express a different opinion, the hierarchic power was strong and rules were there to obey (and never to discuss or to question). To disagree would be to risk prison, torture, or even death (Reis, 1996). In patients’ testimonies this situation is clear: “I suffered in my own skin, in order to contribute to society’s well-being today... (...) I was arrested because I criticized society... I suffered things that I tried to forget... I had only bread and water.”(P12)

In patients’ testimonies, the obligation to obey, as well as the fear to speak and to claim a voice, is clear. Thus, it may be considered that this culture of obedience is possibly a factor of influence reducing autonomy and patients’ empowerment.

The freedom to decide was reduced to private life affairs, particularly inside the house regarding daily life activities: and at this point it is interesting to note that both patients and nurses agree on the fact that the home was the women’s domain.

Looking back at nurses' testimonies many examples may be found: "My grandmother... she was active and she ruled the house (...) but he [the grandfather] was the opposite: very calm devoted to his readings' (N13). Women kept control over the family and ruled the house, made decisions, cared for the farm. In fact, in 1960, women represented just 20% of employed people. Moreover 47% of all workers were in the primary sector of the economy: agriculture. In addition, women were prevalent in rural activity (Barreto, 2002).

Thus, nurses' descriptions portrayed a society where women really stayed at home and even if they had work they would do it at home, on their own farmland. Men worked outside the house, often abroad, and when they came back they did not interfere much in home decisions. Nurses describe extensively the quiet, peaceful grandfathers who used the time to read or calmly smoke their cigars. Furthermore, as presented in previous chapter, men are quite often absent and often their name is not known. Thus, even though Portugal was a patriarchal and masculine society vis-à-vis political power and social labour issues (Barreto, 2002), inside the house the power was held by women who cared for the family, as it had been for centuries (Collière, 1996).

### ***5.1.2. Older people's portrait***

In considering older people's background in Portuguese society, it could be stated that, even though older participants felt powerless regarding social and political issues, they were able to stay empowered in private life matters, particularly women in domestic issues. With this borne in mind, it is necessary to go back to data to understand older people as portrayed in this study. However, there are quite different portraits of older people in this study as testimonies are reported by different narrators (nurses and older people) vis-à-vis different contexts and different moments in time. Therefore, it became vital to put different profiles side by side in order to highlight differences and similarities.

Consequently, four main profiles of older people are summarized in Table 6: participants' self-portrait prior to hospital admission and during hospital admission and nurses' description of older people in hospital and at home. Nurses' and patients' descriptions of hospitalization are contemporaneous, i.e. describe present or near past experiences. However patients' and nurses' home experiences may have a significant time gap, as described before.

Looking at Table 6, and comparing descriptions of older people at home, one could state that nurses and older patients agree that in their quotidian environment, older people are empowered, keep autonomy and are able to adapt to changes. Thus, it could be said that, despite significant social changes, it seems that the perceptions of nurses and the experiences of older people are very similar. However, a few differences may be noticed: older people self-report physical strength lost and nurses describe older people as cultural teachers.

Table 6 – Comparing nurses' and patients' descriptions

	Nurses' description	Patients' description
<b>Older people at home</b>	Had a family Were hard workers Cared for others Ruled their lives Made their own choices Their decisions were respected Were cultural teachers -----	Have a family Were hard workers but are retired Cared for family members Rule their lives Make their own choices Their decisions are respected ----- Lost physical strength
<b>Older people in hospital</b>	Are a family burden Family neglect them Limited to a bed Lost physical strength Are dependent and need care Obey hospital rules Do not have opportunities to make choices Their decisions are ignored	Have a good relation with family Have a present family Feel limited to a bed ----- Are dependent and need care Obey hospital rules Do not have opportunities to make choices Their decisions are ignored

As far as physical strength being lost is concerned, it is one of the most significant consequences of ageing (Berger and Mailloux-Poirier, 1995). Nonetheless, if strength lost does not have visible effects as regards of functional impairment, it may not be visible to others (Gallo *et al.*, 2000). It is important to remember that nurses' descriptions of older people are based upon their childhood memories and subtle changes probably would not be noticed. On the other hand, older participants consistently described their ability to adapt to changes: "I am still the same person, doing the same things (...) the only difference is that now instead of coming with all that supermarket bags as I used to do... now I go twice a week." (P13). Being able to adapt to changes has already been presented as one of the key issues in keeping autonomy (Heathcote, 2000). However, something that stands out in this excerpt is the declaration: "I am still the same person". This statement proclaims a coherence in life and in actions, referring to autonomy as keeping consistency in actions over time, as defended by Jecker (1993).

The second difference between nurses' and older patients' portraits regards the accomplishment of a social role: being cultural teachers. Many of the nurses' testimonies state, like Nurse 4, that "we should learn from them". In the same way, patients say "young people do not want to listen to us anymore" (P4) or "my grand-daughter says that now we live in modern times" (P12). Thus, it seems that this is one of the significant social changes: in the past, older people were more valued for their knowledge and their experience. However, nowadays, a culture of the "young and the new" has gained expression in all sectors of society: not only related to consumerism but also to changing social values (Barreto, 2002). Young people's opinion is more valued, as they are seen as the future of the nation and older people are seen as representing the past. Regarding this point, what patient 12 says is: "I do not agree but I respect them... and I'm moving along with changes".

With reference again to Table 6, and comparing descriptions of older people in hospital, both nurses and older patients state that older people in hospital are

powerless, limited to a bed, ignored in the decision-making process. Moreover, nurses acknowledge older people's experience of hospitalization as being disempowering, but seem to do little to address this issue. However, since the experience of hospitalization is the core concern of this thesis, this topic will subsequently be discussed in detail. Additionally, patients and nurses have opposite descriptions of family. Nurses describe older patients as a family burden and often abandoned or neglected, yet all patients report having a supportive family. Hence, it is important to explore these contrasting pictures before moving on.

### **5.1.3. Family matters**

Family participation in nursing care has been widely described as fundamental, particularly in the field of geriatric care. Many publications point out improved outcomes in different dimensions, such as the clinical outcomes, the possibility to return home, as well as the recovery, autonomy and quality of life after discharge (Tierney, *et al.*, 1993, Berger and Mailloux-Poirier, 1995, Cabete, 1999, Bull and Roberts, 2001, Barreto, 2002, Roberts, 2002, Shyu and Lee, 2002, Beers, 2005, Cabete, 2005b, Coffey, 2006, Timonen, 2008). Nurses in this study frequently affirm that family is important in care. However, the reality they describe is significantly distant from the desired picture.

According to the nurses' point of view, family is almost absent from care. As one of the nurses stated, "I always remember some situations that unfortunately are frequent: older people that remain in hospital after discharge (...) because their family does not come to take them home, or just because they have no family" (N17; WR). The image of older people in hospital seems to be associated with family burden or even family abandonment and it looks as if nurses are accusing the family of ingratitude by not returning the love and care received in the past: "Most often these people had a hard life, worked a lot to build something and doing the



best they could, a life full of work, full of family...now full of loneliness...” (N17; WR)

This excerpt draws a picture of older people’s situation which recurs quite frequently in the nurses’ narratives: it is the image of people who worked their entire lives for a family that now seems to be unavailable. “And even worse: sometimes when family knows that discharge is planned they stop visiting the patient and quit responsibility. Older people are often considered as a burden.” (N19; DN) So it looks as if the family do not accept patient discharge and do not take the older patient home, or just disappear: this nurse even says “quit responsibility”, i.e. they do not care and do not want to take the “burden” home. The consequence of family abandonment is also in the data: older patients stay in hospital because it seems that, in the absence of family, other social resources are not available. In fact, in Portugal, the number of rehabilitation beds is almost insignificant and long care units are scarce (Portugal, 2006a). Arguably, this is a more complex situation than just a missing family. However, in nurses’ testimonies the responsibility is attributed to the family.

It was quite surprising and even disturbing to realize that nurses have an overall pessimistic image of the family, particularly because all the patients in this study reported present and committed families. Actually, the patients live with a spouse or, if they live alone, all refer to having regular contact with their family and all receive visitors in hospital. According to the patients’ point of view, even though some older patients express the fear of being a family burden, an engaged family is the rule, not the exception. Moreover, none of them suggested being either abandoned or neglected. Therefore, I revisited data, trying to find out reasons for such different interpretations and two main reasons emerged:

A. Nurses keep in memory extreme situations of family abandonment and generalize those experiences, creating a negative stereotype;

The idea that nurses may be generalizing rare and extreme situations came from one small excerpt: “I remember at least two or three cases of older patients that no one took home” (N7; OR). Thus, besides being one more example of complete family absence, one detail makes a significant difference in this excerpt: “I remember at least two or three cases”. This means that from more than ten years of professional experience nurses kept in their memory not the hundreds or thousands of older patients with a family, but the two or three cases that had no one to care for them. One of the possible reasons that might explain why nurses talk so much about abandoned older patients is related to the fact that witnessing situations of abandonment may be shocking and, thus, those experiences may remain in the memory (Cabete, 2008). As this nurse said: they didn’t have nobody... or if they did, anybody wanted to take them home or everyone was too busy. And they stayed... stayed in the ward... and stayed there until they died... that’s it! (N7; OR). And, in fact, nurses describe older people’s abandonment in terms of emotions such as pity, grief, compassion or indignation towards family or society. Nurses consider that it is unfair that someone who has worked all her or his life for society and family, at the end of that life does not have social dignity or family support. As one of the nurses said, “the big ending deserved to be better” (N5, OR).

B. The family has changed due to social changes and nurses keep expectations mirroring a family model that no longer exists.

The second reason that may explain such dramatic differences between the nurses’ and the patients’ point of view may be related to different expectations regarding family role. It may be that nurses nourish the idea of the family of the past, as in their childhood, having three or more generations under the same roof, with stay-at-home mothers (or daughters) completely available to care for whoever needed care. It may be that older people have adapted to family changes over past decades and nurses have kept the image of the family of their childhood, as well as keeping the image from their past of unimpaired older people.

In fact, society has significantly changed, as acknowledged by all participants in this study. In their testimonies, nurses state that nowadays families are smaller, grandparents no longer live with the younger generations in the same house and children move from rural to urban areas. And Portuguese statistics confirm this: while in 1960 nearly 44% of employed people worked in primary sectors of the economy (particularly in agriculture), in 2002 only 7% remained; in the same period in the industrial sector, the percentage rose from 28.9% to 37.9%, while in the tertiary sector it shot up from 27.5% to 55%. Moreover, women are now half of the national workforce. Families have, on average, 2.7 members, and it is becoming rare that more than two generations live in the same house. There are more couples living together without marrying, the number of marriages having decreased significantly; there are more divorces and fecundity rates have decreased below generation reposition level (Barreto, 2002).

Actually, statistics change because people's behaviour changes. Moreover, all these changes might have influenced not only older people from different generations but also the way nurses look at older people. However, as far as the patients are concerned, it seems that they were able to adapt to changes in the course of time. As one of the older participants says: "And well... that's life, things change... and I... little by little... I've been adapting to changes... I'm moving along with changes... slowly... because if we do not adapt... we'll be out!" (P12). Thus, it seems that being able to adapt to changes is an important key to keeping autonomy. In addition, keeping social awareness seems to be essential to achieving autonomy, as stated before, "Life has changed, but while I'm aware I will rule my world!" (P12). Thus, it seems that, despite what happens around one, what really matters is to have the power to rule one's life. In other words, it could be stated that autonomy is kept to the extent people are able to adapt and to keep control over their environment, as described in the literature (Heathcote, 2000). Moreover, in order to keep in control of one's life, it is necessary to have empowerment self-awareness, i.e. have a clear perception of this control and a

belief that one can influence external events (Shiloh *et al.*, 1997, McAllister *et al.*, 2008).

Summarizing family matters, it could be argued that nurses make a dichotomist family assessment: either the perfect family from their past or the neglectful or non-existent family. However, whenever nurses play the role of being “the family” many insights occur, as, beyond discovering what the main family needs are, they also identify family feelings and fears. Furthermore nurses felt shocked by their colleagues’ unethical behaviours and became aware of how wrongly their own previous performance could have been. In addition, nurses feel overwhelmed by the pressure of social expectations vis-à-vis a perfect and ever-present family, aggravated by the fact that by being nurses, their own entire family transfers to them all the expectations and the responsibility for care.

The pressure on family caregivers is not a novelty as hospital stays tend to be shorter and the complexity of care tends to be higher. This brings additional stress to family caregivers and increases the need for information and support (Coffey, 2006). Nonetheless, nurses in this study only realized the relevancy of it whenever they were themselves family caregivers. Hence, there is a need to encourage deeper reflexion among nurses in order to help them to assess family resources and needs adequately; allowing them to integrate family members in care, providing them with the training or the knowledge they need, thus contributing to a more successful patient transition from hospital to home (Cabete, 1999).

## **5.2. The experience of hospitalization**

When nurses talk about older people in hospital they describe dependent and powerless people, without physical strength who are confined to bed and need care. When patients describe themselves in hospital they draw a picture of powerless people, ignored in decision-making and dependent on care. Furthermore, nurses describe that patients are invisible to physicians, who make

all the decisions and ignore the patients' will. Patients describe physicians as almighty decision-makers who almost totally ignore their will and presence. Hence, it seems that everybody agrees on the picture of powerlessness.

With reference once again to the metaphor of a movie script, it could be stated that everyone agrees on the actors' portrait: they are powerless and their autonomy seems to be lost. Yet the point is that the action of the movie is more important than the actor's picture: in the action there are feelings and emotions, expectations and outcomes coming from the interaction between actors. And, at this level, the tensions start to emerge from the data.

Namely, it could be argued that both nurses and patients appreciate "the good patient profile" (e.g. nurses like patients who do not disturb and patients do not like to disturb). However, on the other hand, patients describe feelings of anger related to dependency and powerlessness and they claim for a voice. Furthermore, patients report the fear to talk, to ask questions or to complain when facing inhuman and unethical behaviours, stating that there is a long way to go until older patients succeed in being listened to in health care settings. And above all, the argument of this movie is about autonomy and empowerment. However, regarding this issue, patients' and nurses have different points of view.

Therefore, there is a need for a wider discussion and, in regard to this, through analysis of the data, some core issues have captured my attention; namely, the power of actors (physicians, nurses, patients and family) and the power of deeply-imprinted practices (rules and routines).

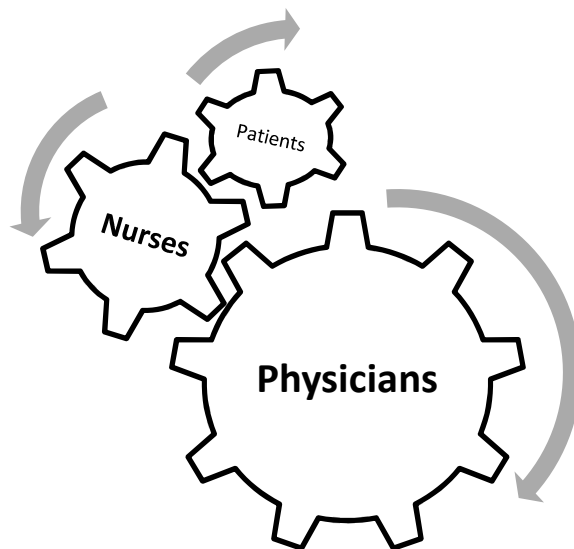
### ***5.2.1. The power of actors***

According to participants' unanimous testimonies, physicians are the ones in charge in hospital. However, the issue is not as simple as that, as power dynamics in hospital result from the complex interaction between many actors, particularly patients and their families, nurses and physicians. Thus, I would like to use the

metaphor of a gear (in Figure 16) to discuss power relationships, keeping in mind that I only have the point of view of two groups of actors: nurses and patients.

Looking at Figure 16, one of the first interpretations is: wheels have different sizes. In fact, according to participants, the strongest link belongs to physicians: they have the strength and the power to decide, even against the other links. This mirrors the dominance of the biomedical paradigm, where the effort is not to achieve a mutual understanding or goal setting but where the stronger link is the engine of all the wheels, which must move in a direction and at a speed determined by the stronger one. And this is the very opposite of empowerment (Mapanga and Mapanga, 2004). Hence, in Figure 16, different wheels sizes are proportional to the amount of power the nurses and the patients attribute to each actor.

Figure 16 - The power of actors



### **Physicians' and nurses' power**

In spite of not being frequently present in nurses' narratives, physicians play a significant role as they influence decision-making and patients' self-determination in a negative way. In the first place, nurses report physicians' therapeutic disinvestment, giving examples of age discrimination and unethical care. However, nurses in this study admit they feel powerless to question physicians whenever decisions are opposite to a patient's will. In previous chapter, many examples were given of physicians' disrespect towards older patients' will. However, even if nurses disagree or feel indignation, in the end, they abide by the physicians' will. It could be argued that nurses lack the empowerment or the assertiveness to be the patients' voice. Thus, I would agree with the authors who state that "a disempowered profession cannot empower clients" (Shearer and Reed, 2004).

Hence, nurses are not able to question physicians' attitudes or decisions and to argue assertively. However, it seems that nurses are not aware of this. Nevertheless, nurses have a clear perception of patients' inability to confront health professionals' decisions, particularly physicians' decisions: "They [patients] never question a professional's decisions, hardly ever... And with the doctor is even worse, it's difficult" (N6; IV). This same nurse affirms that doctors visit beds, or files, instead of patients, make decisions without asking patients' opinion and even ignore their presence as if they are not important. They do not speak the same language as patients, who do not contest their decisions because they are afraid of retaliation. Moreover, patients also make themselves invisible: keep quiet, do not ask and do not argue: "They shut down, they do not say a word and we know that is because they fear retaliation, or due to lack of information... they keep quiet... and even more with the doctor"(N6; IV). Older patients particularly do not ask questions. Only younger patients have the courage to challenge physicians' paternalism and almighty power: "Younger patients, nearly 30 years old... may be...Thank God! But not elderly people... no... they are not

used to” (N6; IV). In addition, it is declared that nurses know why patients keep silence: either they do not have enough information or they are afraid of the possible consequences. Moreover, the nurse is saying that the patient’s submission is a generalized behaviour of patients in hospital towards all professionals, but she is particularly critical regarding the physician-patient relationship.

Moreover, besides this, it seems that according to the nurses’ point of view, health professionals also like to have the power of decision. In addition, health professionals do not want to relinquish the power they have; particularly physicians, who, even when the patient or the family do not agree with some medical decision, always find a way of keeping medical power: “Health professionals are very zealous of this... of that territory, of our space, and we don’t want to relinquish...” (N8; OR). Moreover, it is stated that whenever patients disagree with medical decisions, health professionals find a way of keeping them: “No problem... you do not want to do this now, but today or tomorrow if the patient gets worse we will do it as an emergency and that’s it!” And thus they skip the authorization requirement” (N8; OR). So the message seems to be that health professionals will prevail anyway as in an emergency situation patients’ permission is not needed. However, what is remarkable is that the nurse includes herself in the picture: she says “we” (meaning everybody), not “they” (just pointing the finger at physicians’ power). This mirrors a strong biomedical paradigm, with the focus on disease and not on people (K  rouac *et al.*, 1994, Hesbeen, 2000, 2004, Honor  , 2004).

### **Patients versus decision-making models**

Patients are the gear’s weakest link: everyone has power in hospital but them. Furthermore patients’ testimonies totally agree on this position: “Having power? What power? (...) Here everyone gives orders and we have to obey (...) patients



have to obey, we do not have any decision power” (P6). It is the general view that patients are at the bottom of the hierarchic chain.

However, patients make a clear distinction between the power held by nurses and that held by physicians. Regarding physicians’ action, patients acknowledge that they have the knowledge to make decisions because they know the diseases and the treatments and whatever is the best in a particular clinical condition. Patients say: “Regarding disease doctors decide. We should not interfere, because we do not have the knowledge to discuss it! They must decide and we must obey. They know what the best is for us” (P11).

Thus, at the same time, patients describe physicians’ almighty power but also state they are the ones entitled to make clinical choices. Patients do not expect (or want) to decide what kind of treatment or diagnostic procedures should be undertaken. What patients do not like is to be ignored or treated like objects, i.e. sometimes they feel invisible as physicians visit beds instead of patients, discuss things between them, ignoring a patient’s presence, and do not communicate decisions. Moreover, a real informed consent seems to be absent as patients are able to say that informed consent is much more than simply being given some forms to sign.

With regard to decision-making models, it could be argued that older patients in this study do not expect to develop a relationship with physicians based on partnership, as described in the shared decision-making models and that they feel comfortable with the paternalistic model, as described by authors (Charles, Gafni and Whelan, 1997, Gafni, Charles and Whelan, 1998, Charles, Gafni and Whelan, 1999, Charles *et al.*, 2006, Montori, Gafni and Charles, 2006, Murray, Charles and Gafni, 2006). Apparently, older patients do not want to have the responsibility to decide therapeutic interventions, not because they do not care but because they trust in doctors who have the knowledge, the expertise and the experience to choose the best options. However, patients would like to be informed about what

is going on, to be asked about how they feel and what their needs are, and to give (or not) a real informed consent to medical procedures. As one of the patients said: “I’ll have surgery, doctors decided (...) there is no choice (...) but I really appreciated that the Director came here... he more or less... gave me a light explanation” (P6). Hence, patients position themselves closer to the paternalistic model, as described in the literature, as long as they receive information about decisions and a real informed consent is sought (Beisecker and Beisecker, 1993, Charles, Gafni and Whelan, 1999, Charles *et al.*, 2006).

Regarding patients’ relation to nurses, the scenario is quite different, as, while physicians make decisions that patients do not feel able to assume, nurses manage the activities of daily living, those matters which patients usually control in their own environment and feel perfectly able to do: “Nurses also make their decisions... and decide what we must do... now you have to bath, now you have to eat... and it’s fast... let’s go! You have to eat! And we quit complaining (...) we are afraid!” (P6). Hence, patients position themselves close to the shared decision-making model vis-à-vis the nurse-patient relationship (Charles, Gafni and Whelan, 1997, Charles, Gafni and Whelan, 1999, Charles *et al.*, 2006, Montori, Gafni and Charles, 2006).

### **Change in nursing care is needed**

In the patients’ descriptions, nurses are firstly presented as nice and good, treating patients well but overloaded by work. However, afterwards, patients say that some professionals do not listen to older people, do not address their needs adequately, are authoritarian and have behaviours that are not respectful; namely, not respecting clients’ privacy by exposing their bodies, not answering to calls, ignoring requests, yelling at patients, telling them off or forcing them to eat or to bath. However, in many cases, patients say “but not here” or “not now”. Hence, patients often close their eyes, pretending to be asleep, pretending not to see, or they even try to sleep in order to help time pass; and, even when it is the present

situation which patients described negatively, patients do not complain because they fear retaliation. Similar experiences of lack of respect have been reported in other studies (Hellström and Sarvimäki, 2007)

This picture is very far from an empowering environment. Moreover, as I went through patients' testimonies, I started to understand that authoritarianism, unethical behaviours and lack of compassion were quite frequent. Such behaviours are a clear violation of the Deontological Code of Practice of the Portuguese Council of Nurses (OE, 2004). Furthermore, they lead to disempowerment as they develop a learned helplessness by exposing people to situations they are not able to control (Seligman, 1975, Faulkner, 2001a). Additionally, older people do not complain owing to fear of retaliation or abandonment, which is also referenced by many authors, especially in nursing homes (Ambroggi, 1989, Dodds, 1996, Meddaugh and Peterson, 1997, Solum, Slettebo and Hauge, 2008). Moreover, it may be also that a powerlessness situation in itself may turn communication into a hard task: it may be difficult to talk if nobody seems to listen. And nurses should be the voice of the voiceless (Henderson, 1978) and not the silence keepers. However, finally I realized that these older people were really complaining, as they were taking the risk of sharing those experiences with me. This conclusion made me believe that these older people were looking to be listened to and claiming a voice, as they were able to take the risk of expressing their feelings and emotions, to describe their experiences and deepest worries to someone they did not previously know. I was willing to listen and, by doing so, I was opening the way for their voices to be heard and contributing to participants' empowerment.

Hence, older patients want to be listened to and to be part of the decision-making process regarding daily care. Furthermore, they would like to be considered as with full rights partners. A humanized and competent approach is needed, able to respect older people and to identify patients' needs adequately (Hesbeen, 2000). Furthermore, it seems that older people would stand up to shared decision-making

models regarding nursing care (Charles, Gafni and Whelan, 1997, Charles, Gafni and Whelan, 1999).

### ***5.2.2. The power of rules and routines***

Traditionally, nursing cultures are characterised by rigid routines, rituals and care delivery organized to meet the needs of nursing staff of ward administration. The needs and wishes of individual patients are not the focus during care delivery: the nurse determines the priority of needs rather than the patient (Tonuma and Winbolt, 2000).

This statement fits perfectly into this study, as both nurses and patients talk about rules and routines in hospital which create barriers to patients' freedom of agency. The vague expression often used "there are rules patients must follow" raises the questioning about these assumed rules. Nurses even use the expression "inflexible rules". However, going through the data, some contradictions emerge, as the supposedly inflexible rules are not written anywhere and many of them do not make any sense. In addition, many of these so-called rules are even opposite to best-practice guidelines both from the Portuguese Council of Nurses and from the National Health Service (OE, 2001, Portugal, 2002, 2006b). Some of those supposed rules described both by older patients and nurses are:

- The patient must bath every day; at the earliest possible in the morning;
- The patient should eat all the food displayed on the tray;
- The patient should not receive visitors without nurses' prior consent;
- The patient should avoid calling the nurse;
- The patient should abide by nurses' rules;
- Patients should not enter the nurses' room;
- Patients should be next to their beds at all times.

Arguably, none of these sentences corresponds to an effective rule. Instead, they reveal nurses' need for the patient to fit into staffs daily routines (Tonuma and

Winbolt, 2000). As one of the nurses said, “rules are in people’s minds and they are just a tradition that nurses are used to following” (N6). Once more the issue is the focus on tasks and not on patients. And even if patients are not happy with this state and even if nurses acknowledge that such rules do not make any sense, they are not able to change this because they consider it institutionally difficult and disturbing to the nursing team. Once again, nurses follow a biomedical paradigm (focusing on tasks rather than on people), adopt a paternalistic attitude (by assuming control of the ward’s daily routine) and feel powerless, as they do not feel capable of changing routines and questioning established traditions or practices, either in their own team or, even less, at an organizational level. These attitudes and behaviours contribute to patient disempowerment and to a poor quality of nursing care (Collière, 1996, Charles, Gafni and Whelan, 1999, Hesbeen, 2000, Collière, 2001, Hesbeen, 2001, Thompson and Thompson, 2001, McCormack, 2003, Hesbeen, 2004, Pereira, *et al.*, 2005).

Thus, a critical discussion is needed in order to clarify what care management is (for example, to organize care according to staff availability) and what is just automatic behaviour, reproducing unquestioned routines along the exercise of authoritarianism. Older patients have already done this critical analysis, as they state they understand that the care must be organized according to good management rules and that the care delivery schedule depends on staff availability. As one of the older participants said, “some people think that someone has to be near them all day and all night. It cannot be because we are so many and staff is short, we know” (P1). Furthermore, “we understand that it is not possible to have someone to help patients to bath at whatever time... it wouldn’t be good management (...) but we would like those rules to be explained” (P16).

Therefore, it seems that neither nurses nor patients are happy with a ritualistic approach to care, based on some non-existent rules, or with an organization of care which focused on task accomplishment, rather than being patient centred. In the literature, it is also possible to find examples where “when nurses perform

good work and remain committed to excellence, they experience fulfilment as they contribute to the well-being of their patients” (Miller, 2006). And this same author identifies some obstacles to good work in nursing: “nurse shortage, demands on time, conflicting values among peers, lack of autonomy and the growing emphasis on productivity”. Almost all of these factors may be found in participants’ testimonies: both patients and nurses are aware about the shortage of nurses and about staff reductions. Furthermore, patients clearly identify that some nurses are there for the money and others for the patients, which exemplifies conflicting values between peers. However, there is a further conflict: between nurses’ humanistic values and their practice. Nurses are able to identify what they consider as inappropriate care (e.g. ignoring the individual needs of each patient). In addition, nurses acknowledge having been task oriented, rather than patient centred.

Following rules and meeting group expectations is acknowledged as an attribute of low professional development, as broadly described by Benner (1984). However, considering that nurses start working at a beginner level, in a few years’ time they should reach the competent level, i.e. a level where critical reasoning should be present and autonomous practice should emerge. However, it seems that, regardless of the number of years spent in practice, some nurses remain at the beginner level; that is to say, they are unable to question the reasons behind the gestures. And it seems that nurses do not feel they have the necessary autonomy to change practices they criticize. This may be culture-related but, on the other hand, it may also reveal professional disempowerment (Kane and Thomas, 2000, cited in Shearer and Reed, 2004).

Nonetheless, organizational culture may significantly influence the care delivered and patient satisfaction, as well as professional performance and staff satisfaction. In a culture oriented to managed care, nurses may feel voiceless and just work to accomplish tasks. It is necessary to give nurses a voice in the organization at all decision levels in order to change organizational culture, allowing nurses to

pursue excellence through patient-centred care (Lewis, 2009). And this is only possible if top decision-makers are engaged in the process and acknowledge nurses' value inside the health system. In other words, everyone needs to feel they have the same value in the organization regardless of what kind of role they play (Craigie and Hobbs, 2004, Wallin, *et al.*, 2006). However, in this study, it seems that nurses do not feel they have any power in the organization, as they do not even dare to change any kind of routine. To involve staff in the decision-making process may lead to evidence-based care replacing a routine-based behaviour (Newman, Papadopoulos and Sigsworth, 1998, Wallin *et al.*, 2006).

### **5.3. The concept of autonomy**

The concept of autonomy has been a core issue all through the previous chapters. Hence, now is not the moment to start a discussion about autonomy, but it is the moment to go back to data, to revisit descriptions and interpretations and to come out with a renewed and summarized concept, encompassing patients' and nurses' points of view. However, first and foremost, I must say that this summary is one possible reading of the participants' testimonies, shared at a particular moment in time and in a particular context. Thus this is not an exhaustive exploration of what the concept of autonomy might be to acute care older patients, but the most reliable interpretation possible of the shared experiences of sixteen older patients and twenty nurses. And through this interpretation some new contributions may be given in order to broaden the understanding of older people's autonomy in the context of acute care.

The concept of autonomy in nurses' narratives seems to rely on the decision-making process but is particularly focused on tasks performance skills, i.e. nurses consider autonomous the individuals who rule their lives, both at the decision-making level and at the physical level. In other words nurses described as autonomous those persons who had the freedom and the willingness to make

decisions, along with the necessary information that allowed them to do so, to communicate this and to accomplish their wishes. To nurses, the most visible outcome of autonomy is independence in performing self-care, which is strongly dependent on functional performance.

As one of the nurses stated: “I do not know so many autonomous older patients” that is to say, as patients usually have some functional impairment, hence nurses assume that autonomy is almost non-existent. Hence, I would agree with the authors who state that, in spite of its being a much-used term in nursing care, it is often used as synonymous with achieving high scores in some task performance measurement scales (Boyle, 2004, Cabete, 2005b, Calnan, Badcott and Woolhead, 2006, Boyle, 2008). Thus, nurses reduce the concept of autonomy to fully active persons, such as older people from their childhood memories. Those older people made their own decisions, had control over their lives, ruled the family, worked and cared for others. On the opposite side are old people in hospital, who do not have the necessary physical strength to perform self-care; thus, it seems that they are also forgotten in the decision-making process.

In the literature, independence is acknowledged as being a component of autonomy. However the point is not only the action but the control over the action (Jacelon, 2004); that is to say, having the power over decision and action. However, among participant nurses, it seems as if whenever one of the preconditions of autonomy is impaired, all remaining skills are ignored. Moreover, nurses just point out autonomy as depending on a patient’s skills and do not value environmental influences (namely, nurses’ action) as significant determinants of autonomy. In other words, it seems that patients’ autonomy in hospital is the patients’ matter and not also an outcome of nurses’ interventions.

Therefore, it seems that autonomy is measured by its manifest expressions, in terms of visible actions, e.g. performed self-care. In the absence of these manifest expressions, nurses fail to assess the existing skills, not seeing the potential of



each person i.e. what autonomy could be if there were opportunities, freedom and encouragement. Hence, nurses not only expect patients' dependency and submission but also expect them to rely on their decisions. By doing so, fewer opportunities are given to older people to participate in the decision-making process, and autonomy is threatened, as described in the literature (Boyle, 2008). And even though nurses' actions are based upon beneficent principles, they are carried out in a paternalistic way (Charles, Gafni and Whelan, 1999). In addition, patients' testimonies reveal dissatisfaction with nurses' paternalistic actions.

Considering the patients' point of view, autonomy encompasses four dimensions:

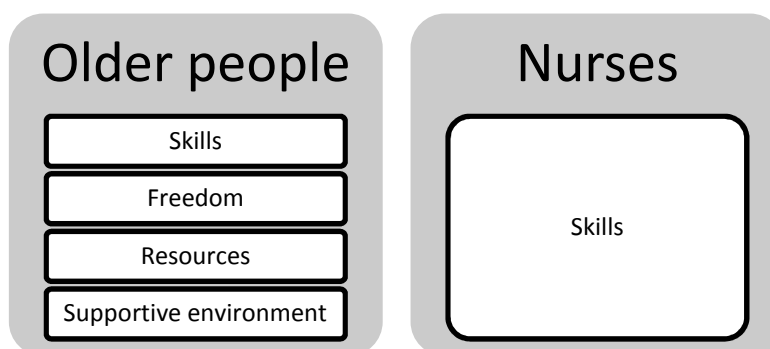
- Having freedom: to think, to speak, to decide, to act, to abide by one's rules;
- Having resources: housing, family, financial independence, social support;
- Having skills: physical and cognitive skills allowing them to keep self-awareness, to manage the activities of daily living, to be able to keep one's routines and to be able to adapt to changes;
- Having a supportive environment (in order to be entitled to make choices and to have freedom of agency according to one's values).

In hospital, patients are aware of which autonomy dimensions they keep and which ones are environmentally dependent. Patients acknowledge illness imposes restrictions, and are able to cope with it. Nonetheless, patients express frustration and even anger, towards authoritarianism and blind hospital rules. Furthermore, patients say they are in prison (i.e. they lost freedom) and that they do not have a supportive environment, as they have to follow other people's rules (namely nurses' rules). In addition, their opinion is ignored and their will is often disrespected.

Hence, considering patients' and nurses' experience and testimonies, I would say that patients have a broader understanding of autonomy than nurses. And, putting

side by side older people's and nurses' most significant determinants of autonomy, as schematized in Figure 17, it is possible to see that patients and nurses have different concepts of autonomy and that nurses have not yet reached the same understanding as patients.

Figure 17 - Autonomy according to nurses and older people



Hence, patients in this study would agree with Heathcote's (2000) statement that autonomy encompasses "control over one's life, opportunities to make choices, and feeling comfortable about developing and using one's personal resources". Patients also would undersign the statement that "it is better to die than to lose one's autonomy" (Heathcote, 2000) as the idea that hospital is like hell, or like a prison is more than once expressed. Thus, besides what autonomy means, the issue raised in this study is also related to the extent to which patients are able to manifest the underlying autonomy they have. And this reflexion led the idea that there is a **latent autonomy**, that people want to develop and to use, and a **manifest autonomy**, the one people actually succeed in using. Furthermore, as I did not find these concepts in the literature, I would dare to state that perhaps this is the original contribution to knowledge of this thesis. Moreover, because this study is about older people's autonomy in acute care settings, I would like to develop this idea, staying as closer as possible to the patients' point of view.

### ***5.3.1. What is latent autonomy?***

In the first place, latent autonomy may be defined as one's ideal of self-determination, the willingness to rule one's life according to inner resources. It is not a utopia but an individual construct considering one's skills, potential and environment. And, as exemplified by participants in this study, to some people it may be related to being an independent worker; to not having bosses. To other people, it may be living alone, without having to give justifications to parents, to children or to spouses. To other people, it may be related to maintaining freedom of speech, to abiding by one's own rules, without fear of any physical, psychological, social or political retaliation. It may be related to "attaining majority" (P14), or "to have one's money" (P6). But it could be summarized as "to be who I am" (P1). As one of the patients said, it is a comprehensive understanding of an overall independence encapsulated in the expression "I always owned myself" (P2).

However, it is important to underline that the independence described by older participants as the ideal of autonomy, is much beyond nurses' concept of independence, which is almost reduced to physical independence. To older patients, independence means being entitled to make decisions and having freedom of agency.

Looking at Jacelon's (2004) study, in which older patients in acute care settings defined autonomy as having independence (in terms of physical performance) and control over actions (i.e. self-perceived power), I would say that participants in this study raised a broader concept. Thus, although describing independence in terms of having physical strength to execute one's decisions, patients also include a form of psychological independence, i.e. self-awareness skills and a willingness to make decision. Moreover, patients also talk about social independence (having their own house, having enough money, having access to social resources). Finally, the ultimate independence is freedom: freedom to decide what to do,

freedom of movement, freedom to express feelings and emotions, freedom to be oneself and even freedom to make mistakes. Furthermore, freedom also exceeds the concept of control over actions: it is related to self-determination and empowerment and it is strongly dependent on human environment.

Hence, latent autonomy may be considered as the projection of one's self-determination, resulting from willingness, sense of purpose, freedom of decision and freedom of agency, taking into consideration one's skills, values, resources and environment. As one of the older participants says, "Autonomy is what we are, knowing what we are, knowing what we do, knowing what we are going to do ahead." (P1). Latent autonomy is the vision of what one believes one is able to be, and to accomplish, despite physical impairment or external circumstances. As one of the patients says, "Things may change (...) but while I'm aware I will rule my world" (P12). Patients acknowledge that illness imposes some limitations but, in spite of this, they continue to be able to decide whether they want to eat or not and whether they want to bath or not. Thus latent autonomy seems to be an individual concept, quite stable over time, as each person has her or his own ideals. Moreover, older participants state that, despite the ageing process, illness or hospitalization, they are still the same persons. But on the other hand each individual adjusts her or his concept of latent autonomy according to internal and external resources. In hospital, for example, patients clearly understand illness and clinical procedures impose limitations. But they are perfectly aware of how they would like to be treated and what they are still able to do.

### ***5.3.2. What is manifest autonomy?***

Manifest autonomy is the real outcome of latent autonomy at a particular moment and in a particular context, resulting from the interaction of the four components of autonomy described by older participants: individual skills, internal and external resources, freedom of agency and environmental constraints. Many

examples are pointed out by older participants. Keeping cognitive skills is fundamental to keeping self-awareness and to adjusting one's goals to individual resources. However, when resources are scarce, the autonomy possible is reduced: not having enough money or not having access to health care or social benefits decreases the available options. Not having a voice in society owing to political reasons, for example, makes people experience fear and so they quit complaining and to claiming for their rights. Moreover, freedom of agency is compromised. Having to abide by other people's rules will diminish autonomy. Not being in one's house is one of the examples cited most often in participants' recitals.

In hospital, due to biomedical focus, and because patients are outside their environment, patients are not able to materialize their latent autonomy. Sometimes, what alone remains is the freedom to think. All other dimensions of latent autonomy are compromised.

Hence, manifest autonomy is latent autonomy turned into actions. Thus, it may not be a stable outcome because what is really achieved is circumstantial in each moment and in each context. Besides, its uniqueness is also due to the fact that latent autonomy is an individual construct. But even if latent autonomy may remain the same, manifest autonomy is the real achievement.

However, manifest autonomy is not just doing things and it is not reduced to physical performance skills, as many authors underline (Boyle, 2004, Calnan, Badcott and Woolhead, 2006, Boyle, 2008) but the achieved independence and control over actions (Jacelon, 2004). Moreover, it is dependent on material, educational and emotional resources (Boyle, 2008).

### ***5.3.3. The gap between latent and manifest autonomy***

Thus, I would say that there is a **latent autonomy** and a **manifest autonomy**. Latent autonomy encompasses older people's willingness, existing skills and potential. Manifest autonomy is the real outcome, what autonomy happens to be at

a particular moment and in a particular context. Moreover, environmental support and patient empowerment are determinant factors that define the distance between latent and manifest autonomy.

At home, where people are in control of their environment, latent autonomy and manifest autonomy are very close: older people decide and do whatever they want, adjusting daily life to their skills and resources, even though older people do identify wider environmental influences, such as social and economical resources. However, in hospital, manifest autonomy becomes distant from latent autonomy, owing to lack of attention, hospital rules and routines, biomedical paradigm and health professionals' authoritarianism or simply lack of awareness.

Nevertheless, it is possible to help people to keep manifest autonomy as close as possible to latent autonomy, if human environment is supportive, i.e. if family or nurses are willing to help patients to overcome difficulties. Nonetheless, to help patients in the achievement of their autonomy, nurses need to be aware of what autonomy is to older people.

Thus, considering the topics raised in the literature reviewed, I would agree with Davies et al. (2000), who say that autonomy in nurses' discourse is a widely-used but poorly defined word. Moreover, autonomy (to nurses) keeps the stress on task performance assessment, rather than on ethical issues and the patient's dignity, as many authors have pointed out (Boyle, 2004, Cabete, 2005b, Calnan, Badcott and Woolhead, 2006, Boyle, 2008). Nonetheless, nurses in this present study were able to identify more dimensions of autonomy, particularly in recent experiences with their relatives in hospital. Moreover, nurses acknowledged that threats to autonomy are also threats to patients' dignity, which is a fundamental issue in health care, namely on nursing care for older people (Reed and McCormack, 2007).

Therefore, essential work needs to be done with nurses towards a better understanding of what autonomy really represents to older people. In fact, it is

only possible to deliver nursing care if patients' needs are adequately assessed. And to assess patients' needs also consists of knowing what autonomy means to each person.

It may be argued that autonomy, as well as other concepts in health care, may have a different meaning to different people. However, besides concept variability according to distinct points of view, another issue raised in this study is the extent to which older patients are materializing (or not) their autonomy. In other words, it looks as if a core concern to older patients is that they feel unnecessarily deprived of their autonomy. Hence, in hospital, there is a significant distance between the autonomy patients are allowed to have and their underlying potential. And, as the greater the distance between latent and manifest autonomy, the more frustrated, angry and powerless patients feel.

Thus, I would conclude that, besides helping nurses to expand their understanding of patients' autonomy, it is also necessary to draw nurses' attention to the need to assess patients' manifest autonomy as well their latent autonomy. Finally, it is necessary to develop intervention strategies to help older people to bring their potential autonomy to the highest possible level. And empowerment may be one of the possibilities.

#### **5.4. The concept of empowerment**

The concept of empowerment is quite unknown to nurses and, patients and in a first approach, most of the nurses in this study had never heard the word before<sup>17</sup>.

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<sup>17</sup> It is important to remember that the word empowerment does not exist in Portuguese: the English word is used in literature and in the academic environment, in official documents, but not generally in the everyday-language even though the concept should be known by nurses. See footnote number 13, on page 167.

Then after a brief explanation, nurses were able to identify some related situations, particularly regarding disempowering situations. In fact, as Faulkner states (2001a), empowerment is difficult to define, as it means different things to different people and it is more easily understood by its absence than by its presence. Thus I would say that empowerment is largely absent from the nurses' narratives. Nonetheless, a few aspects leading to empowerment are reported: having physical freedom, giving information regarding life styles, allowing patients to control their environment and to be actively involved in decisions (e.g. to live in one's house).

Thus I could say that nurses acknowledge that empowerment involves individuals in interaction with their environment, leading towards self-assertion and control, as described in the literature (Aoki, 2002, Shearer and Reed, 2004, Wehmeier, 2005). Whenever nurses describe situations where older people were taken from their own house to their children's house or to a nursing home, they also recognise that being in a different environment (where rules are dictated by others) leads to powerlessness, reduced autonomy and helplessness, which, in some situations, lead to depression and death, as described in the literature (Faulkner, 2001b). However most of the nurses' references regarding empowerment are placed outside the hospital context, mirroring their difficulties to identify patients' empowerment situations in daily practice.

To older patients, having or gaining power is related to being entitled to do things in their own way. Patients' most-used expression is "to propose and dispose", that it is to say deciding according to one's values and projects, defining rules for one's life and being free to dispose of one's life by not having to give explanations to other people. Hence, older patients in this study would agree with the authors who state that empowerment is "the process by which individuals are enabled to solve their own problems, sort out their own needs and mobilise the necessary resources to be in control of their own lives" (Faulkner, 2001b). To older people, empowerment regards to self-determination and self-government



depending on environment namely on physical and human environment (Gibson, 1991, Faulkner, 2001b, 2001a, Aoki, 2002, Shearer and Reed, 2004). For this reason, I would state that empowerment is the process by which latent autonomy is transformed into manifest autonomy.

Regarding the physical environment, housing is a frequently-raised topic among older people. Being the owner of the house gives older people not only the power to control their environment but the authority to make decisions, either regarding daily life issues or broader decisions. At home, individuals set their own rules and do not have to abide by other people's rules. Independently of economical conditions, the value of having a house is translated into the possibility to be "the master of the house".

Moving to other environments is described (both by patients and nurses) as disempowering, because older people's status changes from "master of the house" to "visitor". And, even if, in children's house, the older person is very welcomed and loved, even if there is a room just for him/her, older people feel under the obligation to abide by the host's rules. As one patient said "sometimes we do what they want because we do not want to hurt them, because they care for us". And, if in the children's house empowerment decreases, in a nursing home, the situation is even worse, as is widely documented in the literature (Cohen, 1988, Ambrogi, 1989, Nystrom and Segesten, 1994, Post, 1994, Solum, Slettebo and Hauge, 2008). Further, power in hospital belongs to everyone apart from the patient. In addition, older patients feel ignored and subjugated by health professionals' authority. Thus, having authority conferred by being the owner of the house seems to be important to older patients, who see physicians and nurses as owners of that house named "hospital".

However, another issue related to power at home caught attention: women's power. As stated by Pradhan, to talk about women's empowerment is "in vogue", meaning "women making independent choices, enabling them to emerge from a

subordinate position” (Pradhan, 2003). Furthermore, many authors refer to the need for women’s empowerment in different settings (Browne, 1995, Svedlund, Danielson and Norberg, 2001, Shaw, Mccoll and Bond, 2003, Messias, De Jong and McLoughlin, 2005, Jewell, 2007, Adubra, 2008, Skuladottir and Halldorsdottir, 2008). However, in this study, power and authority inside the house seem to belong more to women than to men: in patients’ narratives (both male and female), it is clear that at home women decide what to do and when to do it, women care for the ill, manage the house and men abide by women’s rules. Also, nurses’ narratives corroborate this idea, using once in a while the word “matriarch”. It could be argued that this is due to the fact that home affairs and caring for the ill were traditionally considered women’s duties (Collière, 1996, 2001). Nonetheless, testimonies emphasize decisions (and not only actions) covering a broader spectrum of life than just illness or health care. This may be a Portuguese cultural issue that would be relevant to explore. However, this is not the aim of the present study.

Outside the walls of home, empowerment seems to be linked to hierarchic power (namely, to labour contexts) and to social status. According to patients, having enough money to address individual needs and having social respect is fundamental to keeping social power. In the same way, economic status (particularly poverty) has been reported in several studies as having a negative impact on empowerment. Also, intervention programmes to improve social participation among poor communities have shown its relevancy (Pradhan, 2003, Messias, De Jong and McLoughlin, 2005, Braunack-Mayer and Louise, 2008). In this study, many patients stated that without minimum economic power the possibility to influence the course of life or social decisions is strongly reduced. Without money, people lose rights and dignity, particularly retired people who are no longer in a position to strike and who have lost social influence over political decisions affecting them. Many patients report reduced power related to having a low income (as well as its consequences for health and well-being). In fact,

Portuguese older people have low income levels which, together with a past history of fascism, diminish citizens' strength and voice (Barreto, 2002).

Another subject brought up by older people was loss of physical strength, as this leads to the impossibility of doing what one wishes. Losing physical strength is described as the major age-related loss, and often the only significant one, as sometimes older people must stop doing whatever they like to do. Moreover, it has an impact on authority. Hence, if the human environment is not supportive, without strength it is impossible to achieve one's goals or to put decisions into action.

The fear of frailty seems to be present as well as a thankful attitude towards relatives, whenever some impairment occurs. The expression "from now on I will have to depend on my children" seems to be linked to the idea that some submissive behaviour is expected. In the literature, this idea of physical frailty in older people is related to a voiceless situation, i.e. older people may be considered too frail to participate in decision-making or may be too grateful to carers to dare to disagree on whatever the latter decide (Barnes and Bennett, 1998). In other words, sometimes the opportunity to participate in decision-making does not exist (as caregivers assume decisions in a paternalistic way). On other situations older people relinquish participation in decision-making to avoid opposing family or professional caregivers, either because they feel grateful or because they fear the consequences of expressing their dissatisfaction (e.g. retaliation or abandonment). And, in this study, there are many examples of this expected submission, not because a formal authority exists but because some form of protectionism is present.

This means that even when caregivers' attitudes and behaviours are based upon beneficent values (and not on authoritarianism) some well-intentioned paternalism (such as over-protecting people) may lead to reduced power because older people feel happy they have help and may fear losing their social support. The result is

forgoing empowerment or abdication from participation in care and in decisions regarding care, already described in the literature reviewed (Kapp, 1989). However, the boundaries between abdication and forgoing empowerment are not easy to draw, just as the presence of some form of authoritarianism is not always so obvious. As Collopy (1988b) says, “care can slide toward control, not from malevolence but simply by the dynamic of powerful and resourceful professionals interacting with vulnerable and resource-weak clients”.

Nonetheless, older patients reported situations where abdication is clear (“I must accept that others will decide” and “I do not want to interfere because I am afraid of losing the care I have”). However, in acute illness, forgoing empowerment is likely to occur. At certain times (e.g. acute illness), it is possible to transfer decision-making power to other people without losing empowerment: this power is transferred to someone trustworthy, a relative with whom the patient has a close relationship (namely a spouse, a son or a daughter), someone who loves the older person and thus will respect her or his values and will make decisions accordingly; that is to say, decisions will be congruent with a patient’s past decisions and life values.

Thus, it seems that older patients have an accurate idea of what empowerment is regarding self-determination and power to rule one’s life according to one’s values and patterns, as well as its interdependency with the social and human environment. Empowerment relies on having the physical strength to execute decisions or enough authority to make someone accomplish these, and a supportive human environment. Moreover, housing and economic issues seem to be relevant because they may increase or reduce an individual’s authority. To nurses, empowerment is a quite unknown subject and it is centred on authority and physical freedom issues. Once more, it looks as if patients have a broader understanding of power dynamics and that they are very aware of this in daily life, as well as in health or illness situations.

## 5.5. Moving towards autonomy and empowerment

The implementation of effective person centred care must take into consideration psychosocial and cultural factors relevant for the patient and for the nurse. A major consideration would be nursing culture, nursing attitudes and management structures prevalent in the specific unit (Tonuma and Winbolt, 2000).

A reading of the outcomes reveals that the overall impression captured from the data is that in the context of hospital care, both nurses and patients mostly describe a disempowering scenario: patients feel powerless and ignored in the decision-making process and are constantly exposed to circumstances that induce helplessness and reduce control over situations. Nurses undervalue patients' awareness, regarding autonomy and empowerment, and are more focused on tasks than on patients. However, some examples may be found regarding actions that seem to contribute to patient's well-being and self-determination, increasing their autonomy and their control over the environment.

- **To use a language that patients are able to understand** – often health professionals use a sort of language that to some patients is a dialect they do not understand, full of professional jargon, reducing the possibilities for the patient to understand what is going on and to hold a dialogue with the health professional. As one of the nurses said, the more educated patients are the ones who are more likely ask questions, as they are more able to understand whatever is told.
- **To give patients the necessary information** – patients need to know what the schedules and routines are. Nurses must explain why it is important to keep seated in the chair instead of being in the bed, or why hygiene care is only available in the morning shift. Just receiving information about what to do and not about why to do it is considered by patients just as mere authoritarianism and leads to patients' anger or apathy. On the other hand if patients know the reasons for actions they feel respected even if they do

not have the opportunity to choose, for example, at what time they will be bathed.

- **To treat patients with dignity and respect** - independently of age, social status, income or education, patients need to be considered as human beings with full rights, and their privacy needs to be respected. Patients need to feel free to refuse to eat or to do anything they do not want, or even to call staff when needed, without the fear of retaliation.
- **To listen to the patient and to assess her or his real needs** – when a patient says that “I have here a nurse that really listens to me, but there are professionals and professionals...” it is clear that listening to patients is essential to provide adequate nursing care, otherwise nurses are just doing a list of tasks and considering patients as “cases” and not as persons.
- **To obtain a truthful informed consent** – to be sure that the patient really understands the therapeutic plan and that she or he feels free to accept or to refuse is vital to a patient’s empowerment. As one patient says, it is not enough to drop in a form to sign or to give a flyer with a few explanations or just say to patients whatever they must do.
- **To give patients the freedom of agency** – is to try, by all means, to ensure that the patient understands the reasons for the clinical recommendations but that she or he has also the right to accept these recommendations or not, without being coerced. More than this, it is important to accept patients’ right to be free and even the right to make mistakes. As the oldest patient said, by doing so he managed to reach the age of 91.
- **To accept patients and their families as real nursing care partners** – by nurses being assertive and listening to patients’ needs, by discussing aims, possibilities and expectations regarding nursing care, patients feel more in control of their lives and of their situation. By involving families

during the whole hospital stay, difficulties will be identified, skills will be developed and resources will be found earlier. Moreover, patient and family will feel more in control of the situation.

Finally, it is vital that nurses develop self-awareness regarding autonomy and empowerment issues in the context of acute care of older people. And, first and foremost, it is important to state that all along this journey, together with twenty nurses, many insights happened and horizons were widened through moments of discussion, of shared experiences, of reflexion and of silence. The experience of doing biographic work is in itself a learning experience, both for participants and for the facilitator (Josso, 1991, Dominicé *et al.*, 1998, Josso, 2006, Cabete, 2008). Furthermore, although to explore ways of developing nurses' awareness and critical thinking skills was not the aim of this thesis, I truly believe in its value, following many years of my own experience in using it with nurses.

From all the examples of nurses' awakening to a renewed understanding of older people's autonomy and empowerment, one of the most meaningful examples is the situation reported by Nurse 8, regarding the use of physical restraints. In her recital, everything changes on the day when she enters the ward and faces the image of her father under physical restraint: an image of powerlessness, reduced dignity, deprived freedom and helplessness emerged as a paradigmatic example of inappropriate care and lack of humanity. Shocked by the situation, at the same moment, this nurse expresses her anger and deep indignation and acts in order to modify the situation. However, foremost, she questions her own practice. As she says: "I considered myself a competent nurse, though I had done the same many times." Hence, she considered herself as performing humanized care and suddenly she felt indignation towards her own behaviour: "How hadn't I ever realized how wrong this was?" And, finally, her action as nurse changes: "I never used restraints again". And furthermore she succeeded in influencing her team: "I do not allow anyone in my shifts to use physical restraints... ever... and I don't care if they call me Mother Teresa of Calcuta!" In this example, three major steps were

taken to improve quality of nursing care: to learn, to grow and to change (Cabete, 2008). Thus, to discover that something better can be done, to integrate it (cognitively and emotionally) and to put it into practice are core steps to achieve change in care, and, in this particular case, to enhance the patient's empowerment and dignity.

The previous example is a visible and extreme situation of disempowering attitudes. However it is necessary that nurses start acknowledging that hospital rules and routines, paternalism, authoritarianism, biomedical focus, lack of communication, absence of truthful informed consent, patients' inadequate needs assessment (among other examples of disempowerment), may be as strong as physical restraints. Furthermore, such disempowering attitudes and behaviours may be even more dangerous, as they are not as visible as physical restraints.

Hence, it is necessary that nurses start feeling indignation regarding disempowering attitudes, as Nurse 8 felt in the example above. But indignation is not enough. It is also necessary to integrate empowering ways of caring and to move forward by putting the renewed knowledge into practice.

Nonetheless, it is important also to take into account that to achieve a significant change in practice needs more than nurses' awareness, as patients' autonomy and empowerment are also dependent on social, organizational, economic and political factors, as discussed earlier in this thesis. Some issues raised by participants such as the shortage of nurses, the prevalence of the biomedical paradigm in health care in many contexts, the hospital culture and deeply-imprinted practices, the lack of social and health resources available to patients and to families, patients' culture of obedience (a heritage from a dictatorial past), are just a few examples of the large scale of change needed to achieve optimal care. Thus, I would say that citizenship awareness is also needed, as well as social and cultural transformation, in order to give older people the autonomy and dignity they are entitled to have in acute care settings.



## 6. CONCLUSION

At the end of this journey it is time to look back, to assess the work done, to summarize contributions to knowledge and to look forward. The way done was as challenging, as rich and intense. The endeavour was to explore concepts of autonomy and empowerment of hospitalized older people, in the context of acute care in Portugal through phenomenological research and hermeneutical analysis. Moreover, I wanted to include both nurses' and patients' point of view, as to give voice to patients is also a contribution to their empowerment. Hence, for almost one year, testimonies of nurses and patients were collected, searching for the answer to the research question: "How do nurses and patients experience autonomy and the empowerment process in hospital?" But before moving forward (and considering the research design and method) it is very important to be aware that the conclusions of this study are valid in the context in which they were produced i.e. in acute care settings, in Portugal, and that they represent the participants' experiences.

At the end of this stage it is important to overview the process, in the light of the methodology used, in order to consider possible generalization of data. But, in the first place, it is also relevant to underline that the motivation to do this study was related to the need to give a contribution to the fulfillment of a gap in literature: in fact, the concepts of autonomy and empowerment are not a novelty, but its recent exploration has been focused on the context of long term care, namely in nursing homes. Moreover, older people's voice has not been frequently heard. Thus this study aims to bring an insightful exploration of autonomy and empowerment in the context of acute care for older people, encompassing nurses' and patients' voices. To achieve it, a qualitative exploration trail was chosen and methodological choices were made.

Hermeneutic phenomenology is a way to knowledge through the exploration of individuals' experiences, life histories being a comprehensive approach of such

experience (Byrne, 2001). Consequently the researcher relies not only on participants' willingness to share their life histories (Kleiman, 2004) but also on participants' awareness of the phenomena (Cohen, Kahn and Steeves, 2000). For that reason, it is required that participants understand what autonomy and empowerment are in order to obtain narratives with noteworthy data. In other words, one is able to describe his or her experience of autonomy and empowerment in the extent he or she understands what these concepts are. And this may be a limitation of this study. Furthermore, autonomy being a more popular concept than empowerment, narratives describe more autonomy related events than empowerment related ones. Nonetheless both concepts are comprehensively portrayed.

Accordingly, the narratives produced by participants in this study mirror their personal understanding of autonomy and empowerment in a certain moment of their lives. Consequently, the hermeneutic task consisted in bringing a comprehensive interpretation (my interpretation, through my own experience and understanding) (Gadamer, 1979) of autonomy and empowerment, intersecting patients' and nurses' experiences. But if in a phenomenological study the outcomes portray participants' experience, in a particular moment in time, in a particular context, it is important to question how to generalize data, i.e. to what extent the findings may have sense in another context (Koch and Latimer, 2006). In fact, 'the findings of an hermeneutic phenomenological research stand alone to be read by others, who begin their own interpretative efforts facing the same problem of meaning' (Cohen, Kahn and Steeves, 2000) in similar or different contexts.

One of the main conclusions is that patients and nurses have different ideas about the concepts of autonomy and empowerment, and that patients have a more comprehensive view. In addition patients in hospital feel powerless, voiceless and perceive that their autonomy is reduced. Moreover, they would like to hold more power regarding the dimensions of care that are currently dependent on nurses'

action. Furthermore, through analysis, interpretation and discussion, a renewed understanding of autonomy emerged, as it seems that older patients differentiate latent autonomy (their potential, existing skills and willingness) from manifest autonomy (the real outcome of autonomy, possible at each moment and in each context, resulting from interaction between latent autonomy and environmental constraints). In hospital, manifest autonomy is distant from latent autonomy owing to patient disempowerment, leading to anger, frustration and reduced dignity. In addition, patient empowerment seems to be one of the possible ways to reduce the gap between latent and manifest autonomy.

Owing to the fact that this differentiation between latent and manifest autonomy was not found in literature, I would advocate the exploration of this idea in different and similar contexts as well as in different populations. In fact, talking about reducing the gap between latent and manifest autonomy is talking about maximization of patients' resources and makes sense in other nursing care contexts and populations. Hence further research is needed to explore the generalization of this finding.

Nonetheless, it is important to be aware of what autonomy and empowerment mean to hospitalized older people, to identify reasons for lack of empowerment in hospital and to reflect on the implications on the nursing care of older people.

## **6.1. The meaning of autonomy and empowerment**

One of the aims of this study was to explore nurses' and older people's concepts of autonomy and empowerment in hospital. According to older people, autonomy means:

- Having the freedom and the skills to make choices influencing their life, both at an instrumental level and on a daily basis, but also, in a broader way, over the lifespan;

- Having the freedom of agency without feeling as if one is at the bottom of a hierarchic chain;
- Making decisions consistently over the lifespan, according to one's values; to have congruence throughout life;
- Continuing to make decisions in spite of environmental or physical constraints, not by ignoring these, but by taking them into account and knowing that there are boundaries;
- Being able to adapt to changes through the ageing process in order to keep routines, but also being able to ask for help whenever it is needed.

According to patients, the only significant difference brought by the ageing process is a decrease in physical strength; if no other significant changes occur, nothing alters regarding autonomy. If however, some functional impairment occurs (due to illness or to dramatically decreased physical strength) older people will depend on the human environment in order to maintain autonomy. Sometimes, they will need some help to move forward with their decisions; this interaction with the environment (either at home or in hospital) involves empowerment.

Empowerment to older patients is:

- Having (or achieving) the authority to execute decisions or to have someone to help them on the accomplishment of whatever was decided;
- Having (or gaining) the power to set the rules for action;
- The way and the means through which autonomy is acted upon and achieved.

Hence, it seems that, to older people, empowerment is the way and the means by which a *latent autonomy* (the existing skills and the sense of willingness) is transformed into a *manifest autonomy* (i.e. accomplishing decisions through an interactive relationship with the environment, taking into account possible

constraints). Older people seem to be clearly aware of these two dimensions because they describe their own skills as well as the limits imposed in hospital. Whenever older participants describe themselves at home, they describe a latent autonomy very close to their manifest autonomy. They know exactly their strengths and their own limits and feel owners of their own lives. However, when they move into their children's house the gap between the decisions they are able to make and the ones they really make starts to emerge. As one of the participants said, "in other people's house I must follow their rules, even if there is a welcoming environment". So the distance between latent and manifest autonomy increases as older people renounce decision-making. In hospital, this gap is even greater, as the environment is completely unfamiliar and unknown. Additionally, either patients feel the need to fit into the "good patient profile" or they fear retaliation. Hence, even if the latent autonomy does not change, the manifest autonomy decreases, as patients do not feel they have any control over their environment.

I could risk saying, following the logic of the Learned Helplessness Theory (Seligman, 1975), that the less older people decide, the less they will be able to make decisions. In other words, the more manifest autonomy decreases, owing to reasons external to patients (such as, hospitalization and nurses' attitudes), the higher is the risk of a decreased latent autonomy, mirroring a snowball effect. In addition, according to older people's narratives, a disempowering environment is closely related to an increased distance between latent and manifest autonomy, i.e. the more disempowered they feel, the bigger the gap is. Besides, to older patients, nurses play a key role in this scenario. Thus, it is important to know what the nurses' perception of this issue is.

To participant nurses, the autonomy of the older people they care for means having the skills to make decisions, to communicate these and to put them into practice, i.e. decision-making skills that must be accompanied by functional performance. Thus, nurses consider as autonomous those individuals who are able

to do what was decided. In spite of acknowledging autonomy as a broad concept, nurses tend to adopt a narrow vision of autonomy, which does not differentiate autonomy from independence. It seems that only the tangible dimensions of autonomy are visible in hospital, mirroring a nursing care philosophy that values the meeting of a list of (also tangible) human needs. Nonetheless, the wide meaning of autonomy is present in these nurses' narratives regarding their older relatives.

Nurses assume that older patients in hospital are not autonomous, because their concept of autonomy relies on physical freedom. Hence as patients have reduced functional performance (due to acute illness, the clinical recommendations for bed-rest or just because patients are supposed to be near a bed) autonomy is assumed to be absent and someone other than the patient must make decisions. As nurses nourish the idea that family members are not willing to care for older relatives, they feel entitled to assume control of the situation and even though nurses may act according to the principles of beneficence, they do so in a paternalistic way.

Empowerment was a subject largely unknown to participant nurses who had difficulties to describe examples from their clinical practice. Nonetheless, in the biographic seminar, nurses developed some knowledge about this concept. They acknowledged that empowerment is an important issue in the field of the care of older people and that they often assume the role of decision-maker on the patient's behalf, without being asked to do so. They also recognised the need to develop critical thinking skills and to reflect on their practice.

## **6.2. Reasons for lack of empowerment in hospital**

In hospital, patients consider that nothing changes regarding their latent autonomy, particularly in a short hospital stay. However, empowerment is felt to be lost in longer stays, i.e. the possibility of transforming latent autonomy into a

lived and manifest autonomy is removed. Patients maintain the willingness and the skills, but the freedom is lost. They lose power to make decisions and even when they are able to make them and to communicate these, they are often ignored because routines, authoritarianism and a biomedical model speak louder than patients.

Regarding diagnostics and treatment, patients consider that physicians are best placed to make decisions and they feel comfortable about not having to decide. However, real informed consent is important to patients and seems absent in this relationship. Regarding nursing care, patients would like to be real partners in decision-making, as nurses assume decisions that patients feel absolutely able and entitled to do.

As a consequence of being ignored and exposed to situations they do not control and as a result of staff's authoritarianism, patients feel almost invisible and tend to stop speaking or complaining and express fear of retaliation. In addition, they often do not have the presence of a family member in hospital to support them, someone trustworthy and who understands their needs.

Moreover, older patients in this study did not feel happy when nurses' actions were limited to helping them to perform tasks they were unable to do without help. Older people seem to need more than a simple fulfilment of tangible needs. It is not enough to help them to bath, to dress or to eat. More than the help "to do", older patients express the need to have the freedom and the resources "to be". They wish for the acknowledgement of their integrity as human beings, to be listened to, as they are able to have a critical vision of their health and needs, to be released from rules that are meaningless to them and to be helped to find the meaning of the ongoing care process. Older participants would like nurses to see the person behind the needs, the intangible behind the tangible: **a nursing care able to identify latent autonomy and to empower older people in order to enhance manifest autonomy.**

Older people in this study acknowledged their interdependence with the environment and would like to have more supportive human relationships in hospital, according to “non-paternalistic values that are related to human autonomy and freedom of choice” and “an emphasis is placed upon helping a person gaining more self-knowledge, self-control, and readiness for self-healing regardless of the external health condition” (Watson, 1999). Moreover, older patients would like to be partners and co-participants in humane care.

It may be suggested that nurses and patients have different philosophical frameworks: while nurses think in tasks, older patients think in terms of freedom of decision and action. Arguably, nurses are failing to meet patients’ needs, as they are failing to assess accurately what these needs are. However, it is important to consider whether nurses and patients really have different frameworks, or if there are other reasons behind these two apparently different perspectives. For example, when nurses leave their professional caregiver role, i.e. when the hospitalized older patients are nurses’ relatives, they expect more than task accomplishment: they expect that their relatives receive an empowering care that places the patient’s manifest autonomy as close as possible to their latent autonomy.

Nonetheless, it seems that in their professional role nurses are not able to perform the care they know they should practise. Hence, it may be that nurses and patients do not have different philosophies but it might be a matter of nurses’ competencies, which led me to the Dreyfus and Dreyfus model, adopted by Patricia Benner to describe nurses’ performance levels (Benner, 1984, Benner, Tanner and Chesla, 1996). According to this model, it is possible to rank nurses’ performance in five different competency levels: beginners, advanced beginners, competent, proficient and expert nurses. “Beginners have minimal capacity to attend to the patient as a person” and their attention is captured by the list of things to be done, and advanced nurse beginners “cannot readily expand their vision to the patient’s past experiences or future expectations” and they just



“attend to patient’s physical and technologic support” (Benner, Tanner and Chesla, 1996, pp. 49-50). The competent nurse though, has “an increased clinical understanding, technical skill, organizational ability and ability to anticipate the likely course of events” (Benner, Tanner and Chesla, 1996, p.78) and her focus is on managing the clinical condition of the patient and less on getting tasks organized. However, “she has not yet developed the experiential wisdom and ability to integrate ethical and clinical concerns” (Benner, Tanner and Chesla, 1996, p.82). The proficient nurse is the transition level to the expert nurse, where “advanced levels of understanding” require experiential knowledge. At this level, nurses must gain “a more holistic clinical grasp”, as the proficient nurse must be able to have a comprehensive understanding of the patient, as well as to be able to assess changes through time. Between the competent nurse and the expert nurse, there are qualitative huge differences, the latter being able to put care into perspective, not only regarding a timeline (past, present and future); she is also able to discuss ethical implications of care and the focus for action is not on a particular point of the organization of care but on addressing patients’ global needs and expectations.

According to this analysis of nurses’ practice, it could be argued that perhaps nurses in this present study are performing somewhere between the advanced beginner and the competent levels as they focus on tasks accomplishment and on the fulfilment of a certain number of tangible needs.

However, there are signals of nurses’ concern with older persons’ dignity, of their ability to anticipate potential problems, of their acknowledgement of ethical dilemmas, of the recognition of patient’s right to have a more humanized and empowered care. But, despite some ability to recognize the need for patient empowerment, nurses are unable to overcome some passivity when facing situations that are disempowering for the patient. Hence, it might be that, in some situations, nurses may be reaching the proficient level but they fail to accomplish empowering nursing care. They seem to be unable to change the course of action,

as if they were powerless and subjugated by the rules they cite or by institutional power or even by the power of other actors, namely physicians' power. And, powerless nurses will not be able to perform empowering care.

### **6.3. Implications of this study**

One of the major implications of this study is the acknowledgement that older people in hospital feel powerless and claim a voice, as their skills and their willingness to participate in care are underestimated. Hospitalized older people have a latent autonomy significantly higher than their manifest autonomy and nurses play a significant role in the extent of the gap between these two dimensions. Sometimes, nurses seem to feel powerless and patients' dignity seems to be lost.

Thus some changes in individual, professional and institutional practice should take place in order to provide empowering care and enhance patients' autonomy. A possible way to achieve it is moving from a biomedical paradigm and a paternalistic decision-making model to a patient-centred care (McCormack, 2001, McCormack, 2003). This is not an easy move and it challenges institutional culture to pursuit excellence in care (Lewis, 2009). Further research would be necessary to explore ways of changing these particular practices. However, based on participants' contributions, some suggestions could be given to start the movement:

- To have adequate ratios of staff, allowing safe and humanized care;
- To promote a wider discussion on institutional rules and regulations, clarifying the difference between real rules and some routines that do not make any sense;
- To promote a wider discussion and dissemination of patients' rights;

- To give patients written and oral information about organizational rules and client's rights;
- To increase nurses empowerment by allowing them to participate in all decision-making levels;
- To create opportunities for nurses to reflect on practice ;
- To promote multi-professional discussion groups, in order to balance power-relationships and achieve real team-work;
- To develop a policy of family inclusion in care;
- To encourage the development of patient-centred care;
- To encourage patients and their families to give suggestions to improve care.

As far as nurses are concerned, I would suggest the following practices:

- Make explicit to patients the care plan;
- Respect patients' rights, namely the right to participate in decision-making regarding care;
- As far as possible negotiate schedules and always explain the reasons of rules and routines;
- Be assertive and encourage patients to express their feelings and emotions;
- Look for possible reasons for patients' fear of retaliation, trying to minimize it;
- Have in mind that the hospital environment is a constraint on patients' autonomy;
- Be aware that autonomy is much beyond functional performance.

Hence, it is fundamental to develop nurses' awareness regarding the need to become "the voice of the voiceless" (Henderson, 1978) through empowering interventions, adopting attitudes and behaviours that might transform patients' latent autonomy into a vivid and manifest one. In order to achieve this, it is necessary to increase nurses' critical thinking skills. Reflection on practice becomes essential and the biographic approach seems to be a powerful tool, as nurses in this process largely expressed that, in such a safe environment, they felt comfortable to think, to question, to discuss, without the fear of being judged or punished. Thus, I would support the use of biographic methodology, either in under or post-graduate education or even in life-long learning programmes. Accordingly, to explore the efficacy of this methodology would be relevant in further research.

Moreover, to expand nurses' understanding of autonomy and empowerment (and its value on the context in geriatric acute care) would be a challenge for nurse educationalists, in order to enable students to look beyond the surface and to get closer to patients' perceptions and needs. Therefore, there is a need to examine undergraduate nursing education and question if the curriculum promotes a patient-centred approach and if it prepares students to listen to patients.

However, education is not enough and nurses need to be able to put their competences into practice. To do so it is vital to discuss rules, routines, rituals, cultures, practices in order to develop health care providers' awareness (both that of individuals and of institutions) and to open the way to the change that patients want to see and need to have. Furthermore, this discussion must be supported by nurse managers and institutional and policy level decision-makers. Last, but not the least, it is vital to empower nurses because knowledge and willingness might not be enough to move from the proficient to the expert practitioner level: nurses must feel themselves empowered in order to perform empowering care: as cited earlier, disempowered nurses cannot provide empowering care.

Finally, the challenge for nurses is to be able to look at an apparently powerless bed-ridden older person and to discover that there is a latent autonomy that needs to become manifest, that there are projects, wishes, skills and queries in older people's minds, independently of some lost physical strength. In brief, it is necessary to believe that there is life to be lived until the end. The challenge, after all, is to find the essential needs of each older person, knowing that what is essential may be invisible to the eye.

Adieu, dit le renard. Voici mon secret. Il est très simple: on ne voit bien qu'avec le cœur. L'essentiel est invisible pour les yeux.<sup>18</sup>

Antoine de Saint-Exupéry, *Le Petit Prince*.

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<sup>18</sup> 'Goodbye, said the fox. And now here is my secret, a very simple secret. It is only with the heart that one can see rightly. What is essential is invisible to the eye.'

## 7. REFERENCES

- Adubra, A. L. (2008) Non-Traditional Occupations, Empowerment and Women: A Case Study of Togolese Women. IN Fayomi, O. (Ed.) *Gender Matters*. New York and London, Routledge.
- Agish, G. A. (1993) *Autonomy and Long Term Care*, New York, Oxford University Press.
- Ambrogi, D. (1989) Nursing Homes and Residents' Rights. *The Hastings Center Report*, 19, 2.
- ANA (1982) Professionalism and the empowerment of nursing. American Nurses Association.
- Anderson, R. M. and Funnell, M. M. (2005) Patient empowerment: reflections on the challenge of fostering the adoption of a new paradigm. *Patient Education and Counseling*, 57, 153-157.
- Anells, M. (1999) Evaluating phenomenology: Usefulness, quality and philosophical foundations. *Nurse Researcher*, 6, 5-19.
- Anells, M. (2006) Triangulation of qualitative approaches: hermeneutical phenomenology and grounded theory. *Journal of Advanced Nursing*, 56, 55-61.
- Aoki, Y. (2002) Reflexions on Empowerment. *Nursing Older People*, 13, 17-19.
- Aveyard, H. (2000) Is there a concept of autonomy that can usefully inform nursing practice? *Journal of Advanced Nursing*, 32, 352-358.
- Ayme, S., Kole, A. and Groft, S. (2008) Empowerment of patients: lessons from the rare diseases community. *The Lancet*, 371, 2048-2051.
- Baker, C., Norton, S., Young, P. and Ward, S. (1998) An exploration of methodological Pluralism in Nursing Research. *Research in Nursing & Health*, 545-555.
- Ballou, K. A. (1998) A concept analysis of autonomy. *Journal of Professional Nursing*, 14, 102-110.
- Balls, P. (2009) Phenomenology in nursing research: methodology, interviewing and transcribing. *Nursing Times*, 105, 30-34.
- Barnes, M. and Bennett, G. (1998) Frail bodies, courageous voices: older people influencing community care. *Health & Social Care in the Community*, 6, 102-111.
- Barreto, A. (2002) Mudança Social em Portugal: 1960-2000 [Social change in Portugal:1960-2000; Paper published by the University of Social Sciences]. Lisboa, Instituto de Ciências Sociais da Universidade de Lisboa.

- Beers, M. H. (2005) The Merck Manual of Geriatrics. IN Beers, M. H. (Ed.). Merck & Co. Inc.
- Begat, I. B. E. and Severinsson, E. I. (2001) Nurses' reflections on episodes occurring during their provision of care - an interview study. *International Journal of Nursing Studies*, 38, 71-77.
- Beisecker, A. E. and Beisecker, T. D. (1993) Using Metaphors to Characterize Doctor-Patient Relationships: Paternalism Versus Consumerism. Routledge.
- Benner, P. (1984) *From Novice to Expert: Excellence and Power in Clinical Nursing Practice* New Jersey, Prentice Hall.
- Benner, P., Tanner, C. and Chesla, C. (1996) *Expertise in nursing practice: caring, clinical judgement and ethics*, New York, Springer Publishing Company, Inc.
- Berger, L. and Mailloux-Poirier, D. (1995) *Pessoas Idosas, uma abordagem global. [Older people: a comprehensive approach. Book]*, Loures, Lusociência.
- Bergland, A. and Narum, I. (2007) Quality of life demands comprehension and further exploration. *Journal of Aging and Health*, 19, 39(23).
- Biegel, D. E. (1983) Help seeking and receiving in urban ethnic neighbourhoods: strategies for empowerment. *Prevention in Human Services*, 3, 119.
- Boyle, G. (2004) Facilitating choice and control for older people in long-term care. *Health and Social Care in the Community*, 12, 212-220.
- Boyle, G. (2008) Autonomy in long-term care: a need, a right or a luxury? *Disability & Society*, 23, 299 - 310.
- Bradbury-Jones, C. (2007) Enhancing rigour in qualitative health research: exploring subjectivity through Peshkin's I's. *Journal of Advanced Nursing*, 59, 290.
- Brandon, T. (2005) Empowerment, policy levels and service forums. *J Intellect Disabil.*, 9, 321-331.
- Braunack-Mayer, A. and Louise, J. (2008) The ethics of Community Empowerment: tensions in health promotion theory and practice.
- Brown, J. C. and Kanter, R. M. (1982) Empowerment: key to effectiveness. *Hospital Forum*, 25, 6.
- Brown, J. S. T. and Furstenberg, A. (1992) Restoring control: empowering older patients and their families during health crisis. *Social Work in Health Care*, 17, 81-101.

- Browne, C. V. (1995) Empowerment in social work practice with older women. *Social Work*, 40, 358.
- Buffum, M. (2004) Research brief: a study of the empowerment process for cancer patients. *Geriatric Nursing*, 25, 361-362.
- Bull, M. J. and Roberts, J. (2001) Components of a proper hospital discharge for elders. *Journal of Advanced Nursing*, 35, 571-581.
- Byrne, M. M. (2001) Understanding life experiences through a phenomenological approach to research. *AORN*, 73, 830-832.
- Cabete, D. (1999) Cuidados Continuados e Continuidade de Cuidados [Continuous care and continuity of care - Book chapter]. IN Formasau (Ed.) *O Idoso-problemas e realidades*. Coimbra, Formasau.
- Cabete, D. (2001) O impacto do internamento hospitalar no estado funcional das pessoas idosas [The impact of hospitalization on functional status of older people - MPhil thesis]. *Health Psychology*. Lisboa, Instituto Superior de Psicologia Aplicada.
- Cabete, D. (2005a) Guia Orientador do 4º CCFE [Guidance book for the Complementary Year for nurses - Edited by the School of Health ]. Escola Superior de Saúde do Instituto Politécnico de Setúbal.
- Cabete, D. (2005b) *O Idoso, a Doença e o Hospital [Older People, Illness and Hospital -Book]*, Loures, Lusociência.
- Cabete, D. (2007) Avaliação da Construção de um Portfólio de Competências: o processo e os resultados [Building a Personal Skills Portfolio: assessing the process and the outcomes - Peer reviewed paper]. *Percursos*, 2, 4-22.
- Cabete, D. (2008) Histórias de vida nos cuidados de enfermagem [Life histories in nursing care - Research report submitted for public discussion to achieve the grant of Adjunct-Professor]. Lisbon, Escola Superior de Enfermagem de Lisboa.
- Calnan, M., Badcott, D. and Woolhead, G. (2006) Dignity under threat? A study of the experiences of older people in United Kingdom. *International Journal of Health Services*, 36, 355-375.
- Charles, C., Gafni, A. and Whelan, T. (1997) Shared decision-making in the medical encounter: What does it mean? (or it takes at least two to tango). *Social Science & Medicine*, 44, 681-692.
- Charles, C., Gafni, A. and Whelan, T. (1999) Decision-making in the physician-patient encounter: revisiting the shared treatment decision-making model. *Social Science & Medicine*, 49, 651-661.



- Charles, C., Gafni, A., Whelan, T. and OBrien, M. A. (2006) Cultural influences on the physician-patient encounter: The case of shared treatment decision-making. *Patient Education and Counseling*, 63, 262-267.
- Christie, A. (2002) Patient Empowerment or Professional Control? *Physiotherapy*, 88, 54-54.
- Clayton, A.-M. and Thorne, T. (2000) Diary data enhancing rigour: Analysis framework and verification tool. *Journal of Advanced Nursing*, 32, 1514.
- Coffey, A. (2006) Discharging older people from hospital to home: what do we know? *International Journal of Older People Nursing*, 1, 141-150.
- Cohen, E. S. (1988) The Elderly Mystique: Constraints on the Autonomy of the Elderly With Disabilities. *Gerontologist*, 28, 24-31.
- Cohen, M. Z., Kahn, D. L. and Steeves, R. H. (2000) *Hermeneutical Phenomenological Research - A Pratical Guide for Nurse Researchers*, Thousand Oaks, Sage Publications, Inc.
- Collière, M.-F. (1996) *Promouvoir la vie*, Paris, Masson.
- Collière, M.-F. (2001) *Soigner, le premier art de la vie*, Paris, Masson.
- Collopy, B., Dubler, N. and Zuckerman, C. (1990) The Ethics of Home Care: Autonomy and Accomodation. *The Hastings Center Report*, 20, S1.
- Collopy, B. J. (1988a) Autonomy in Long Term Care: Some Crucial Distinctions. *The Gerontologist*, 28, 10-17.
- Collopy, B. J. (1988b) Autonomy in Long Term Care: Some Crucial Distinctions. *Gerontologist*, 28, 10-17.
- Corben, V. (1999) Misusing phenomenology in nursing research: Identifying the issues. *Nurse Researcher*, 6, 52.
- Corser, W., Holmes-Rovner, M., Lein, C. and Gossain, V. (2007) A shared decision-making primary care intervention for type 2 diabetes. *Diabetes Educator*, 33, 700(9).
- Covinsky, K. E., Palmer, R. M., Fortinsky, R. H., Counsell, S. R., Stewart, A. L., Kresevic, D., Burant, C. J. and Landefeld, C. S. (2003) Loss of independence in activities of daily living in older adults hospitalized with medical illness: increased vulnerability with age. *Journal of the American Geriatric Society* 51, 451-458.
- Craigie, F. and Hobbs, R. (2004) Exploring the organizational culture of exemplary community health center practices. *Family Medicine Journal*, 36, 733-739.
- Creditor, M. C. (1993) Hazards of Hospitalization of the Elderly. *Annals of Internal Medicine*, 118, 219-223.

- Creighton, C. (1995) Effects of afternoon rest on the performance of geriatric patients in a rehabilitation hospital: a pilot study. *American Journal of Occupational Therapy* 49, 775-779.
- Davidson, M. R. (2004) A phenomenological evaluation: using storytelling as a primary teaching method. *Nurse Education in Practice*, 4, 184-189.
- Davies, S., Ellis, L. and Laker, S. (2000) Promoting autonomy and independence for older people within nursing practice: an observational study. *Journal of Clinical Nursing*, 9, 127-136.
- Dilthey, W. L. (1976) *Selected writings*, Cambridge, Cambridge University Press.
- Dodds, S. (1996) Exercising restraint: Autonomy, welfare and elderly patients. *Journal of Medical Ethics*, 22, 160.
- Dominicé, P., Josso, M.-C., Muller, R., Pfister, M., Equey, F., Stahl-Thuriaux, A. and Turkal, L. (1998) *Les origines biographiques de la compétence d'apprendre*, Genève, Université de Genève.
- Dube, M. W. (2007) Who Do You Say that I Am? *Feminist Theology*, 15, 346-367.
- Dyson, S. (2005) Life History and Zimbabwean Nursing Student: 'Global Boarder'. *Management in Education*, 19, 8-11.
- Entwistle, V. A. and Watt, I. S. (2006) Patient involvement in treatment decision-making: The case for a broader conceptual framework. *Patient Education and Counseling*, 63, 268-278.
- Faulkner, M. (2001a) Empowerment, disempowerment and the care of older people. *Nursing Older People*, 13, 18.
- Faulkner, M. (2001b) A measure of patient empowerment in hospital environments catering for older people. *Journal of Advanced Nursing*, 34, 676-686.
- Fawcett, S. B., Seekins, T., Whang, P. L., Muiu, C. and Suarez de Balcazar, Y. (1983) Creating and using social technologies for community empowerment. *Prevention in Human Services*, 3, 145.
- Folstein, M. F., Folstein, S. E. and McHugh, P. R. (1975) "Mini-mental state" : A practical method for grading the cognitive state of patients for the clinician. *Journal of Psychiatric Research*, 12, 189-198.
- Fontes, C. (2008) Métodos Biográficos [Biographic methods - electronic article]. *Navegando na educação*. Lisboa.
- Fortin, M.-F. (1999) *O processo de investigação - da concepção à realização [The research process from conception to completion - Book]*, Loures - Portugal, Lusociência.

- Freeman, M. (1995) What is called "hermeneutics"? : Review of *Entering the Circle: Hermeneutic Investigation in Psychology* edited by Martin J. Packer and Richard B. Addison, 1989. *New Ideas in Psychology*, 13, 65-69.
- Gadamer, H.-G. (1979) *Truth and Method*, London, Sheed & Ward.
- Gadamer, H.-G. (1994) Foreword. IN Grondin, J. (Ed.) *Introduction to philosophical hermeneutics*. Yale.
- Gafni, A., Charles, C. and Whelan, T. (1998) The physician-patient encounter: The physician as a perfect agent for the patient versus the informed treatment decision-making model. *Social Science & Medicine*, 47, 347-354.
- Gallo, J. J., Fulmer, T., Paveza, G. and Reichel, W. (2000) *Handbook of Geriatric Assessment* Gaithersburg, Maryland, Aspen Publishers.
- Gauthier, B. (2005) *Recherche sociale: de la problématique à la collecte des données* Québec, Les Presses de Université du Québec
- Gibson, H. (1991) A concept analysis of empowerment. *Journal of Advanced Nursing*, 16, 34-41.
- Gillick, M. R., Serrell, N. A. and Gillick, L. S. (1982) Adverse consequences of hospitalization in the elderly. *Social Science & Medicine*, 16, 1033-1038.
- Griffin-Heslin, V. L. (2005) An analysis of the concept dignity. *Accident and Emergency Nursing*, 13, 251-257.
- Grondin, J. (1994) *Introduction to Phenomenological Hermeneutics*, Yale, Yale University Press.
- Guba, E. G. and Lincoln, Y. S. (1989) *Fourth Generation Interpretation*, Newbury Park, California, Sage publications.
- Hansen, T., Hatling, T., Lidal, E. and Ruud, T. (2002) Discrepancies between patients and professionals in the assessment of patient needs: a quantitative study of Norwegian mental health care. *Journal of Advanced Nursing*, 39, 554-562.
- Heathcote, G. (2000) Autonomy, health and ageing: transnational perspectives. *Health Education Research*, 15, 13.
- Heidegger, M. (1984) *El ser y el tiempo*, Madrid, Ediciones FCE España SA.
- Hellström, U. W. and Sarvimäki, A. (2007) Experiences of self-determination by older persons living in sheltered housing. *Nursing Ethics*, 14, 413(12).
- Henderson, V. (1978) The concept of nursing. *Journal of Advanced Nursing*, 3, 113-130.

- Henderson, V. (2007) *Princípios Básicos dos Cuidados de Enfermagem do CIE [ICN basic principles of nursing care - Book]*, Loures, Lusodidacta.
- Hesbeen, W. (2000) *Cuidar no Hospital [Caring in Hospital - Book]*, Loures, Lusociência.
- Hesbeen, W. (2001) *Qualidade em enfermagem [Quality in nursing - Book]*, Loures, Lusociência.
- Hesbeen, W. (2004) *Cuidar neste mundo [Caring in this world - Book]*, Loures, Lusociência.
- Hochwälder, J. and Brucefors, A. B. (2005) Psychological empowerment at the workplace as a predictor of ill health. *Personality and Individual Differences*, 39, 1237-1248.
- Honoré, B. (2004) *Cuidar [Caring - Book]*, Loures, Lusociência.
- Hoose, B. (1994) Book reviews - The dependent elderly: Autonomy, justice and quality of life. *Journal of Medical Ethics*, 20, 60.
- Hughey, J., Peterson, N. A., Lowe, J. B. and Oprescu, F. (2008) Empowerment and sense of community: clarifying their relationship in community organizations. *Health Education & Behavior*, 35, 651(13).
- Hurty, K. (1984) Power in a new key: the hidden resources of empowerment. *Philippine Journal of Nursing*, 54, 56(6).
- Jacelon, C. S. (2004) Older Adults and Autonomy in Acute Care: Increasing Patients' Independence and Control During Hospitalization. *Journal of Gerontological Nursing*, 30, 29.
- Jacobs, M. (1980) Foster parent training: an opportunity for skills enrichment and empowerment. *Child Welfare*, 59, 615.
- Jasper, D. (2004) *A Short Introduction to Hermeneutics*, Louisville, Westminster John Knox Press.
- Jecker, N. S. (1993) Autonomy, justice, and disabled elderly people. *The Gerontologist*, 33, 695.
- Jewell, G. (2007) Contextual empowerment: the impact of health brigade involvement on the women of Miraflor, Nicaragua. *Journal of Transcultural Nursing*, 18, 49(8).
- Josso, M.-C. (1991) *Cheminer Vers Soi*, Lausanne, L'Age d'Homme.
- Josso, M.-C. (1999) Life history and project: life history as a project and 'life histories' attending to projects. *Educação e Pesquisa* 25, 11-23.
- Josso, M.-C. (2002) *Experiências de vida e formação [Life Experience and Education - Book]*, Lisbon, Educa.

- Josso, M.-C. (2006) As histórias de vida abrem novas perspectivas às pessoas [Life histories opening new perspectives to people - electronic article]. *O Direito de Aprender*. Lisbon.
- Kapp, M. B. (1989) Medical Empowerment of the Elderly. *The Hastings Center Report*, 19, 5.
- Katz, R. (1983) Empowerment and synergy: expanding the community's healing resources. *Prevention In Human Services*, 3, 201.
- Kérouac, S., Pepin, J., Ducharme, F., Duquette, A. and Major, F. (1994) *La pensée infirmière: conceptions et strategies*, Laval, Editions Études Vivantes.
- Kieffer, C. H. (1983) Citizen empowerment: a developmental perspective. *Prevention In Human Services*, 3, 9.
- Kleiman, S. (2004) Phenomenology: to wonder and search for meanings. *Nurse Researcher*, 11, 7.
- Koch, T. (1998) Story telling: Is it really research? *Journal of Advanced Nursing*, 28, 1182-1190.
- Koch, T. (1999) An interpretative research process: Revisiting phenomenological and hermeneutical approaches. *Nurse Researcher*, 6, 20.
- Koch, T. (2006) 30th anniversary commentary on Koch T. (1994) Establishing rigour in qualitative research: the decision trail. *Journal of Advanced Nursing* 19, 976-986. *Journal of Advanced Nursing*, 58, 101-102.
- Koch, T. (2006, 1994) Establishing rigour in qualitative research: the decision trail. *Journal of Advanced Nursing*, 53, 91-103.
- Koch, T. and Latimer, J. (2006) Establishing rigour in qualitative research: the decision trail/30th anniversary commentary on Koch T. (1994) Establishing rigour in qualitative research: the decision trail. *Journal of Advanced Nursing* 19, 976-986. *Journal of Advanced Nursing*, 53, 91.
- Leino-Kilpi, H., Välimäki, M., Dassen, T., Gasull, M., Lemonidou, C., Schopp, A., Scott, P. A., Arndt, M. and Kaljonen, A. (2003) Perceptions of autonomy, privacy and informed consent in the care of elderly people in five European countries: general overview. *Nursing Ethics*, 10, 18.
- Levenson, H. (1973) Multidimensional *Locus* of control in psychiatric patients. *Journal of Consulting and Clinical Psychology*, 41, 397-404.
- Levenson, H. (1974) Activism and powerful others: Distinctions within the concept of internal-external control. *Journal of Personality Assessment*, 38, 377-383.

- Lewis, L. C. (2009) Mission Critical: Building a Culture of Excellence. *Nurse Leader*, 7, 20-24.
- Lidz, C. W., Fischer, L. and Arnold, R. M. (1992) *The Erosion of Autonomy in Long-term Care*, New York, Oxford University Press.
- Llewellyn, P. and Northway, R. (2008) The views and experiences of people with intellectual disabilities concerning advocacy: a focus group study. *Journal of Intellectual Disabilities*, 12, 213(16).
- Lothian, K. and Philp, I. (2001) Maintaining the dignity and autonomy of older people in the healthcare setting. *British Medical Journal*, 322, 668.
- Lowes, L. and Prowse, M. A. (2001) Standing outside the interview process? The illusion of objectivity in phenomenological data generation. *International Journal of Nursing Studies*, 38, 471-480.
- Mapanga, K. G. and Mapanga, M. B. (2004) A community health nursing perspective of home health care management and practice. *Home Health Care Management & Practice*, 16, 271(9).
- Marshall, C. and Rossman, G. B. (1999) *Designing qualitative research*, Thousand Oaks, Sage Publications.
- McAllister, M., Payne, K., Macleod, R., Nicholls, S., Donnai, D. and Davies, L. (2008) Patient empowerment in clinical genetics services. *Journal of Health Psychology*, 13, 895-905.
- McCormack, B. (1993) How to promote quality of care and preserve patient autonomy. *British Journal of Nursing*, 2, 338-341.
- McCormack, B. (2001) Autonomy and the relationship between nurses and older people. *Ageing & Society*, 21, 417-446.
- McCormack, B. (2002) The person of the voice: narrative identities in informed consent. *Nursing Philosophy*, 3, 114-119.
- McCormack, B. (2003) A conceptual framework for person-centred practice with older people. *International Journal of Nursing Practice*, 9, 202(8).
- McGuire, M. B. (1983) Words of power: personal empowerment and healing. *Culture, Medicine and Psychiatry*, 7, 221.
- McWilliam, C. L., Brown, J. B., Carmichael, J. L. and Lehman, J. M. (1994) A new perspective on threatened autonomy in elderly persons: The disempowering process. *Social Science & Medicine*, 38, 327-338.
- Meddaugh, D. I. and Peterson, B. (1997) Removing powerlessness from the nursing home. *Nursing Homes*, 46, 32.

- Messias, D. K. H., De Jong, M. K. and McLoughlin, K. (2005) Being involved and making a difference: empowerment and well-being among women living in poverty. *Journal of Holistic Nursing*, 23, 70(19).
- Miller, J. F. (2006) Opportunities and Obstacles for Good Work in Nursing. *Nursing Ethics*, 13, 471-487.
- Montori, V. M., Gafni, A. and Charles, C. (2006) A shared treatment decision-making approach between patients with chronic conditions and their clinicians: the case of diabetes. *Health Expectations*, 9, 25-36.
- Mullins, L. C., Moody, L., Colquitt, R. L., Mattiasson, A.-C. and Andersson, L. (1998) An Examination of Nursing Home Personnel's Perceptions of Residents' Autonomy. *Journal of Applied Gerontology*, 17, 442-461.
- Murray, E., Charles, C. and Gafni, A. (2006) Shared decision-making in primary care: Tailoring the Charles et al. model to fit the context of general practice. *Patient Education and Counseling*, 62, 205-211.
- Newman, M., Papadopoulos, I. and Sigsworth, J. (1998) Barriers to evidence-based practice. *Clinical Effectiveness in Nursing*, 2, 11-18.
- Nielsen, D., Ryg, J., Nissen, N., Nielsen, W., Knold, B. and Brixen, K. (2008) Multidisciplinary patient education in groups increases knowledge on osteoporosis: a randomized controlled trial. *Scandinavian Journal of Public Health*, 36, 346(7).
- Nightingale, F. (1969) *Notes on Nursing - What it is and what it is not*, New York, Dover Publications.
- Nordgren, S. and Fridlund, B. (2001) Patients' perceptions of self-determination as expressed in the context of care. *Journal of Advanced Nursing*, 35, 117-125.
- Nóvoa, A. and Finger, M. (1988) *O método (auto)biográfico e a formação [(Self)biographic Method and Education - Book]*, Lisboa, Ministério da Saúde, Departamento dos Recursos Humanos da Saúde.
- Nunes, B. (2008) *Envelhecer com Saúde [Healthy ageing - Book]*, Lisboa, Lidel - Edições técnicas, Lda.
- Nunes, L. M. (2003) *Um Olhar Sobre o Ombro: Enfermagem em Portugal [Looking over the shoulder: nursing in Portugal - Book]*, Loures, Lusociência.
- Nystrom, A. E. M. and Segesten, K. M. (1994) On sources of powerlessness in nursing home life. *Journal of Advanced Nursing*, 19, 124(10).
- OE (2001) Padrões de qualidade dos cuidados de enfermagem [*Quality standards in nursing care*; Position paper issued by the Portuguese Council of Nurses]. Lisboa, Ordem dos Enfermeiros.

- OE (2004) Competências dos enfermeiros de cuidados gerais [Competencies of the Generalist Nurse - Official regulation document issued by the Portuguese Council of Nurses] Lisboa, Ordem dos Enfermeiros.
- OE (2007) Dados Estatísticos [Statistical data - Official data from the Portuguese Council of Nurses]. Lisboa, Ordem dos Enfermeiros.
- Parsons, T. (1951) *The Social System*, Glencoe: Illinois, Free Press.
- Paterson, B. (2001) Myth of empowerment in chronic illness. *Journal of Advanced Nursing*, 34, 574-581.
- Pereira, M. J. B., Mishima, S. M., Fortuna, C. M. and Matumoto, S. (2005) A assistência domiciliar: conformando o modelo assistencial e compondo diferentes interesses/necessidades do setor saúde [Home Care: configuring the care model and joining different interests/needs in the care sector - Journal article]. *Revista Latino-Americana de Enfermagem*, 13, 1001-1010.
- Perrons, D. and Skyers, S. (2003) Empowerment Through Participation? Conceptual Explorations and a Case Study. *International Journal of Urban and Regional Research*, 27, 265-285.
- Pineau, G. (1983) *Produire sa vie: autoformation et autobiographie*, Montréal, S. Martin.
- Pineau, G. (2006) As histórias de vida em formação: génese de uma corrente de pesquisa-acção-formação existencial [Life histories in education: the outbreak of existential research-action-education - Journal article]. *Educação e Pesquisa*, 32, 329-343.
- Portugal (1999) Decreto Lei nº 353/99 de 03 de Setembro [National legislation regarding Nursing Portuguese Nursing Education System]. IN Educação, M. d. (Ed.). Diário da República.
- Portugal (2002) Ganhos de Saúde em Portugal [Health Gains in Portugal - Official report from the Ministry of Health]. IN Saúde, M. d. (Ed.). Lisboa, Direcção-Geral de Saúde.
- Portugal (2005) Princípios reguladores de instrumentos para a criação do espaço europeu de ensino superior [Official regulation, issued by the Ministry of Science and Higher Education, transposing Bologna Declaration to Portuguese law.]. IN Superior, M. d. C. e. E. (Ed.) 37. Diário da República.
- Portugal (2006a) Centros de Saúde e Hospitais: recursos e produção 2006 [Primary care and hospitals: resources and production 2006; Official report issued by the Ministry of Health]. Lisboa, Direcção Geral de Saúde.



- Portugal (2006b) Programa Nacional para a Saúde das Pessoas Idosas [National Health Program for Older People - Official document from the Ministry of Health] IN Saúde, D. G. d. (Ed.). Lisboa, Direcção Geral de Saúde.
- Portugal (2008) Portal do Governo [Official website, containing the Portuguese government program]. Lisbon, Governo da República.
- Post, S. G. (1994) Autonomy in long-term care: How cherished a value? *The Gerontologist*, 34, 274.
- Post, S. G. (1996) Ethics and long-term care: The continuing discussion. *The Gerontologist*, 36, 414.
- Pradhan, B. (2003) Measuring empowerment: a methodological approach. *Development*, 46, 51-57.
- Priest, H. (2004) Phenomenology. *Nurse Researcher*, 11, 4.
- Prilleltensky, I. and Prilleltensky, O. (2003) Towards a Critical Health Psychology Practice. *J Health Psychol*, 8, 197-210.
- Procter, P. (1981) *Longman Dictionary of Contemporary English*, Harlow, England, Longman Group Ltd 1978.
- Reed, J. and McCormack, B. (2007) Editorial: the importance of dignity. *International Journal of Older People Nursing*, 2, 161-161.
- Reed, J., Stanley, D. and Clarke, C. (2004) *Health, Well-Being and Older People* Bristol, The Policy Press.
- Reed, J., Weiner, R. and Cook, G. (2004) Partnership research with older people - moving towards making the rhetoric a reality. *Journal of Clinical Nursing*, 13, 3-10.
- Reich, S. (1997) Hospitalization in the elderly. IN Baum, A., Newman, S., Weinman, J., West, R. and McManus, C. (Eds.) *Cambridge handbook of psychology, health and medicine*. Cambridge, Cambridge University Press.
- Reis, A. (1996) *Portugal contemporâneo [Contemporary Portugal; Book]*, Lisboa, Publicações Alfa.
- Rentsch, D., Luthy, C., Perneger, T. V. and Allaz, A.-F. (2003) Hospitalisation process seen by patients and health care professionals. *Social Science & Medicine*, 57, 571-576.
- Ricoeur, P. (1990) *Soi-même comme un autre*, Paris, Editions du Seuil.
- Ricoeur, P. (2000) *Teoria da Interpretação [Interpretation Theory - book]*, Lisboa, Edições 70.

- Rimmer, J. H. and Rowland, J. L. (2008) Health Promotion for People with Disabilities: Implications for Empowering the Person and Promoting Disability-Friendly Environments.
- Rispail, D. (2003) *Conhecer-se melhor para melhor cuidar [Developing self-knowledge to achieve better care - Book]*, Loures, Lusociência.
- Roberts, K. (2002) Exploring participation: older people on discharge from hospital. *Journal of Advanced Nursing*, 40, 413-420.
- Roth, P. A. and Harrison, J. K. (1994) Ethical conflict in long-term care: Is legislation the answer? *Journal of Professional Nursing*, 10, 271-277.
- Roth, W.-M. and Tobin, K. (2001) Learning to teach science as practice. *Teaching and Teacher Education*, 17, 741-762.
- Rotter, J. B. (1954) *Social Learning and Clinical Psychology*, Englewood Cliffs, New Jersey, Prentice Hall.
- Rotter, J. B. (1975) Some problems and misconceptions related to the construct of internal versus external control of reinforcement. *Journal of Consulting and Clinical Psychology*, 43, 56-67.
- Rotter, J. B. (1990) Internal vs. external control of reinforcement: A case history of a variable. *American Psychologist*, 45, 489-493.
- Ryan, F., Coughlan, M. and Cronin, P. (2009) Interviewing in qualitative research: the one-to-one interview. *International Journal of Therapy and Rehabilitation*, 16, 309-314.
- Sabin, J. E., O'Brien, M. F. and Daniels, N. (2001) Strengthening the Consumer Voice in Managed Care: II. Moving NCQA Standards From Rights to Empowerment. *Psychiatr Serv*, 52, 1303-1305.
- Sakalys, J. (2000) The political role of illness narratives. *Journal of Advanced Nursing*, 31, 1469-1475.
- Salmon, A. (2007) Walking the Talk: How Participatory Interview Methods Can Democratize Research. *Qual Health Res*, 17, 982-993.
- Savo, C. (1983) Self-care and empowerment: a case study. *Social Policy*, 14, 19.
- Scott, P. A., Valimaki, M., Leino-Kilpi, H., Dassen, T. and al, e. (2003) Autonomy, privacy and informed consent 3: Elderly care perspective. *British Journal of Nursing*, 12, 158.
- Scourfield, P. (2007) Are there reasons to be worried about the 'caretelization' of residential care? *Critical Social Policy*, 27, 155-180.
- Seligman, M. E. P. (1975) *Helplessness: on depression, development and death*, San Francisco, Freeman.

- Shaw, C., Mccoll, E. and Bond, S. (2003) The relationship of perceived control to outcomes in older women undergoing surgery for fractured neck of femur. *Journal of Clinical Nursing*, 12, 117-123.
- Shearer, N. B. C. and Reed, P. G. (2004) Empowerment: reformulation of a non-Rogerian concept. *Nurs Sci Q*, 17, 253-9.
- Shedd, P. P., Kobokovich, L. J. and Slattery, M. J. (1995) Confused patients in the acute care setting: prevalence, intervention and outcomes. *Journal of Gerontological Nursing*, 21, 5-12.
- Shiloh, S., Berkenstadt, M., Meiran, N., Katznelson, M. B.-M. and Goldman, B. (1997) Mediating Effects of Perceived Personal Control in Coping with a Health Threat: The Case of Genetic Counseling. *Journal of Applied Social Psychology*, 27, 1146-1174.
- Shiu, A. T.-Y. (2001) The significance of empowerment for perceptions of control: a case study of a home for older people. *Journal of Clinical Nursing*, 10, 152-153.
- Shyu, Y.-I. L. and Lee, H.-C. (2002) Predictors of nursing home placement and home nursing services utilization by elderly patients after hospital discharge in Taiwan. *Journal of Advanced Nursing*, 38, 398-406.
- Silva, J. F. (2006) *Quando a vida chegar ao fim, expectativas do idoso hospitalizado e família [When life is coming to an end: expectations of hospitalized older persons and their families - Book]*, Loures, Lusociência.
- Simmons, C. H. and Parsons, R. J. (1983a) Developing internality and perceived competence: the empowerment of adolescent girls. *Adolescence*, 18, 917.
- Simmons, C. H. and Parsons, R. J. (1983b) Empowerment for role alternatives in adolescence. *Adolescence*, 18, 193.
- Skuladottir, H. and Halldorsdottir, S. (2008) Women in Chronic Pain: Sense of Control and Encounters With Health Professionals.
- Solum, E. M., Slettebo, A. and Hauge, S. (2008) Prevention of Unethical Actions in Nursing Homes. *Nursing Ethics*, 15, 536-548.
- Stanley, D. (2006) In command of care: clinical nurse leadership explored. *Journal of Research in Nursing*, 11, 20-39.
- Staples, P., Baruth, P., Jefferies, M. and Warder, L. (1994) Empowering the angry patient. *Canadian Nurse*, 90, 28(3).
- Streubert, H. J. and Carpenter, D. R. (2002) *Investigação qualitativa em enfermagem: avançando o imperativo humanista [Qualitative research in nursing: advancing the humanist imperative - Book]*, Loures, Lusociência.

- Suominen, T. and Rankinen, S. (2006) Work-related empowerment experienced by cancer nurses. *European Journal of Oncology Nursing*, 10, 221-221.
- Svedlund, M., Danielson, E. and Norberg, A. (2001) Women's narratives during the acute phase of their myocardial infarction. *Journal of Advanced Nursing*, 35, 197-205.
- Thompson, N. and Thompson, S. (2001) Empowering Older People: Beyond the Care Model. *Journal of Social Work*, 1, 61-76.
- Thornton, J. and White, A. (1999) A Heideggerian investigation into the lived experience of humour by nurses in an intensive care unit. *Intensive and Critical Care Nursing*, 15, 266-278.
- Tierney, A. J., Closs, S. J., Hunter, H. C. and MacMillan, M. S. (1993) Experiences of elderly patients concerning discharge from hospital. *Journal of Clinical Nursing*, 2, 179-185.
- Timonen, V. (2008) *Ageing Societies: a comparative introduction*, Maidenhead, McGraw-Hill Companies.
- Tinoco, R. (2007) Histórias de vida: um método qualitativo de investigação [Life histories: a qualitative research method - Electronic article]. Lisboa, Portal dos psicólogos.
- Todres, L. and Wheeler, S. (2001) The complementarity of phenomenology, hermeneutics and existentialism as a philosophical perspective for nursing research. *International Journal of Nursing Studies*, 38, 1-8.
- Tones, B. K. (1998) Health education and promotion of health: seeking wisely to empowerment. IN Kendal, S. (Ed.) *Health and empowerment: research and practice*. London, Arnold.
- Tonuma, M. and Winbolt, M. (2000) From rituals to reason: Creating an environment that allows nurses to nurse. *International Journal of Nursing Practice*, 6, 214-218.
- Trummer, U. F., Mueller, U. O., Nowak, P., Stidl, T. and Pelikan, J. M. (2006) Does physician-patient communication that aims at empowering patients improve clinical outcome?: A case study. *Patient Education and Counseling*, 61, 299-306.
- UE (1999) Declaração de Bologna [Bologna declaration]. Conselho de Ministros da Educação da Europa.
- Vaartio, H., Leino-Kilpi, H., Salanterä, S. and Suominen, T. (2006) Nursing advocacy: how is it defined by patients and nurses, what does it involve and how is it experienced? *Scandinavian Journal of Caring Sciences*, 20, 282-292.

- Valadez, J. (2003) Response to My Critics. *Philosophy & Social Criticism*, 29, 107-124.
- Wallerstein, N. and Bernstein, E. (1988) Empowerment education: Freire's ideas adapted to health education. *Health Education Quarterly*, 15, 379-394.
- Wallin, L., Ewald, U., Wikblad, K., Scott-Findlay, S. and Arnetz, B. B. (2006) Understanding Work Contextual Factors: A Short-Cut to Evidence-Based Practice? *Worldviews on Evidence-Based Nursing*, 3, 153-164.
- Walsh, K. and O'Shea, E. (2008) Responding to rural social care needs: Older people empowering themselves, others and their community. *Health & Place*, 14, 795-805.
- Watson, J. (1999) *Nursing: Human Science and Human Care: A Theory of Nursing.*, Denver, Jones & Bartlett Publishers
- Wehmeier, S. (2005) *Oxford Advanced Learner's Dictionary*, Oxford, Oxford University Press.
- Weinman, J. (1998) Health care. IN Johnston, D. J. M. (Ed.) *Health Psychology* New York, Elsevier.
- Wengraf, T. (2001) *Qualitative research interviewing*, London, Sage Publications.
- Whitehead, L. (2004) Enhancing the quality of hermeneutic research: decision trail. *Journal of Advanced Nursing*, 45, 512-518.
- WHO (2008a) World Health Organization - Statistical Information System. WHO.
- WHO (2008b) The world health report 2008: primary health care now more than ever. Geneva, World Health Organization.
- Wimpenny, P. and Gass, J. (2000) Interviewing in phenomenology and grounded theory: Is there a difference? *Journal of Advanced Nursing*, 31, 1485.
- Witt, L. d. and Ploeg, J. (2006) Critical appraisal of rigour in interpretive phenomenological nursing research. *Journal of Advanced Nursing*, 55, 215.
- Wu, A. W., Yasui, Y., Alzola, C., Galanos, A. N., Tsevat, J., Phillips, R. S., Connors Jr, A. F., Teno, J. M., Wenger, N. S. and Lynn, J. (2000) Outcomes of Hospitalized Patients Aged 80 Years and Older - Predicting Functional Status Outcomes in Hospitalized Patients Aged 80 Years and Older. *Journal of the American Geriatrics Society*, 48, 6-15.
- Yedidia, M. J. (2007) Transforming Doctor-Patient Relationships to Promote Patient-Centered Care: Lessons from Palliative Care. *Journal of Pain and Symptom Management*, 33, 40-57.

- Zoffmann, V., Harder, I. and Kirkevold, M. (2008) A person-centered communication and reflection model: sharing decision-making in chronic care. *Qualitative Health Research*, 18, 670(16).
- Zoffmann, V. and Lauritzen, T. (2006) Guided self-determination improves life skills with Type 1 diabetes and A1C in randomized controlled trial. *Patient Education and Counseling*, 64, 78-86.